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FOREWORD

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Donald L. Linn 9/28/99
PI - Signature Date

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Introduction:

The goal of this project is to develop methods to encourage earlier detection of breast cancer in rural African Americans. Our previous research has indicated two reasons for late stage breast cancer presentation in this population: 1) lack of breast screening including clinical breast exam and mammography, and 2) patient delay due to cultural and psychosocial beliefs.

Six attitudes or beliefs about cancer have been previously identified which are widely held in North Carolina and which correlate strongly with late stage presentation of breast cancer. These beliefs are: 1) an over-reliance on God to cure cancer without medical intervention, 2) reluctance for a woman to discuss a potential cancer with her husband or male partner because he would not be supportive, 3) a general fatalism that active medical intervention would not make a difference, 4) a specific belief that cutting into a cancer or exposing it to air will make it spread faster, 5) lack of knowledge that a breast lump can be serious even if it does not hurt, and 6) belief in alternative treatments and lack of confidence in surgery as a specific therapeutic modality for breast problems.

The current research seeks to ascertain when these beliefs are formed and test whether they can be modified. Through an extensive educational intervention, we will determine if changing these beliefs increases rates of screening behavior and decreases delay in seeking medical care for breast symptoms.

The experimental design involves community-wide, in depth surveys of women ages 19 and over in two similar counties, Pitt and Wilson. These interviews are being conducted before and after the educational intervention which will be presented only in the experimental county, Pitt County.

Body:

The progress report is organized by tasks to be completed during the reporting period as outlined in the statement of work in the original grant proposal. The only task targeted during this year in the proposal was **Task 4**, conduct the intervention. Overall, we had three main intervention initiatives during the project period. These were: **(1)** conducting educational programs in local churches, civic groups and work sites; **(2)** a television and newspaper advertising campaign using public service announcements and ads developed by the project team; and **(3)** an intervention in local OB/GYN offices, "Generation to Generation," a program asking younger women to talk with their older female relatives about breast cancer. Each of these will be discussed separately with reference to the tasks outlined during the project period. In addition, although not targeted during this year, we conducted work on **Task 3** as we had to continue developing and revising educational materials as the intervention progressed. We also began work in advance on **Task 6**, analyzing results in preparation for **Task 5** to be conducted next year, the post-intervention survey. We needed to determine the significance of our results from the Time 1 survey in order to plan intervention program contents and in order to determine which items would be repeated and which would be modified for the post-intervention survey. Each of these efforts is reported on in the following narrative by task.

Task 4: Conduct Intervention, Months 10-36

a. Hold a one-day educational program on minority health issues for physicians, nurses, and community leaders as a kick-off for intervention

In designing the community kickoff for our intervention year, we decided to hold two separate events, one for the community and one for health professionals. The first, a community-wide kickoff reception was held on Tuesday evening, October 6, 1998 at 6:30 p.m. at the Hilton Inn auditorium in Greenville, NC. Members of the East Carolina Breast Cancer Awareness Project (EC-BCAP) advisory board met in advance to plan the program and to suggest key contact people to invite to the reception. One thousand invitations (see copy in Appendix A) were printed and mailed to these key community members as well as to all of the breast cancer survivors in Pitt County. In addition, the invitation was printed in the local newspaper for three weeks and advertised widely in the local media. Attendance was outstanding. We had 250 people at the reception and over half were African-Americans.

EC-BCAP had a registration table in the lobby, and we asked all attendees to register and to indicate on the registration form if they would be willing to serve on a lay speaker's bureau or to help us arrange a program for a church or community group (see Appendix A for a copy of the registration form used). In addition, EC-BCAP literature, including a bookmark listing mammography sites and our brochures, was available (see copies in Appendix A), and the local chapter of the American Cancer Society provided an information table. A buffet supper was held prior to the beginning of the program so that people could meet and talk with one another.

The program (see copy in Appendix A) began with a welcome by the Mayor of the city of Greenville. Dr. Lannin, project PI, then presented the project goals and plans

for the intervention year. The EC-BCAP advisory board was introduced, and then the intervention video, *To Live On*, featuring six breast cancer patients from eastern NC was shown. After the video, those patients and their families were introduced to the audience and thanked for their willingness to help with our educational programs. The keynote speaker for the event was Sylvia Dunnavant, author of *Celebrating Life: African American Women Speak Out about Breast Cancer*. The evening concluded with an inspirational benediction from Rev. Randy Curtis, chaplain at Pitt County Memorial Hospital.

The local television stations attended the kickoff event and featured video coverage on the local newscasts. An article on the event also appeared in the Greenville newspaper and later was reprinted in several newspapers in other areas of eastern NC. (see Appendix A for a copy of the newspaper story) The feedback from the event was extremely positive, and a number of African-American survivors reported that this was the first time they had acknowledged publicly having had breast cancer. We think it set an inspirational tone for the intervention project and helped build a great deal of public support for our later efforts.

The second was a day-long, breast cancer seminar for health professionals. This event, co-sponsored by the Leo W. Jenkins Cancer Center and the NC Chapter of the American College of Surgeons, was held on Thursday, December 3, 1998 at the East Carolina University School of Medicine. The program covered information on breast cancer screening, diagnosis and treatment advances (see Appendix A for a copy of the program). Dr. Donald Lannin, PI, presented the findings from our survey conducted in year one of the project and discussed the upcoming intervention programs planned for Pitt County. In addition, the intervention video, *To Live On*, was shown and was highly regarded by the physicians attending the conference.

b. Train medical health professional and lay health educators

We used four main avenues to recruit speakers for our speaker's bureau. We first approached members of the EC-BCAP advisory board to ask that they either participate or suggest individuals who would be good. We also recruited from all of the community members attending the kickoff. We subsequently recruited from lay speakers already assisting the local chapter of the American Cancer Society and from members of active breast cancer support and survivor groups. Our fourth avenue was to recruit from the group of African-American lay health advisors trained as part of the Partners Breast Cancer Education Project in Pitt County to work with educating African-American women in local churches.

Our speaker's bureau training was held on Saturday, January 23, 1999 and included lunch for all participants. Twelve African-American and eleven white women (twenty-three total) completed the training. Those trained included eight health care workers (nurses, nutritionists, physicians, and health educators), two medical students, nine breast cancer survivors, and three Partner's lay educators (see complete list of speakers in Appendix B).

Each participant was given a training manual in advance of the session (see a copy in Appendix A). Project investigators Lannin, Mathews, and Mitchell; Project Manager, Frances Swanson, and Ms. Becki Cotner, a Methodist minister and breast

cancer survivor, assisted with the training session. We began by having Dr. Mathews and Ms. Cotner actually take the trainees through a sample educational program as if it were being presented to a local church or civic group. The trainees experienced the program as the audience.

After that presentation, Dr. Lannin presented some background on our research and planning for the intervention and covered the six main beliefs that lead to late stage presentation. He emphasized that our educational program is planned to address these through the video and discussion afterward. Mrs. Swanson reviewed the educational content of the project manual, and Ms. Cotner then worked with trainees on different techniques to generate small group discussions after the video, and trainees then practiced in small groups facilitating discussion. After lunch, we went over the factual materials included in the training manual and Mrs. Swanson discussed the logistics of scheduling and carrying out the programs in the community. Each lay speaker trained was asked to try and personally schedule at least two programs in groups with which they were affiliated.

c. Final revision of materials and implementation of intervention

c.1. educational programs for churches, civic groups, and work sites

Our final materials for the educational programs were assembled prior to the start of programming. We ordered canvas tote bags and stocked each bag with a copy of the video, a copy of the manual, a comment sheet for the educator to fill out and evaluation forms for seminar attendees to complete (see Appendix A for copies). In addition, copies of the bookmark and brochures were included for distribution. Advertisements were placed in the local newspaper indicating that the program was available, and letters were sent out to all civic and religious organizations in the county informing them about the availability of the program (about 200 letters in all). When it became apparent that these letters did not generate much response, the project manager and a student office assistant personally visited many Pitt County businesses, retail stores, churches, and schools in an attempt to encourage these sites to schedule our program. This effort did result in the scheduling of presentations for the employees of the JC Penney store and one of the local Hallmark card shops. One of our lay speakers, Mrs. Cindy Maynard, is a radiation/oncology nurse and the wife of a local Methodist minister. She compiled a list of scriptures from the Bible that bring hope and comfort to families coping with cancer. We reprinted this list and provided it to speakers as an option they could make available to interested audience members (see Appendix A for a copy).

As groups called into the main office to schedule programs, Mrs. Swanson, project manager, scheduled speakers to conduct the programs. She also assisted local groups in preparing flyers and advertisements announcing their programs in local neighborhoods. Speakers went in teams to conduct programs. New speakers were paired with members of the project team for their initial experience and once they gained confidence, we then paired them with new speakers until everyone had experience. We also made every effort to ensure that at least one African-American speaker attended events at African-American groups. By early September of 1999, we had conducted 51 educational programs in churches, civic groups, and at work sites. These were attended

by 784 women. Overall, 15 programs were presented to predominantly African-American groups, 25 to predominantly white audiences, and 11 to mixed audiences. A large number of programs are scheduled to be completed in September and October of 1999 prior to the beginning of the post-intervention survey in November of 1999. A complete list of programs held each month is included in Appendix B.

The main problems encountered in conducting the programs were cancellations. Prior to September of 1999, we had two programs canceled because of inclement weather, as organizers feared a low attendance would result, and one was canceled because the group did not have enough time on the agenda for the video. In two other cases, the speaker showed up at the appropriate date and time, but the meeting had been canceled and the speaker was not informed in advance. We have made every effort to reschedule these programs. We are now facing a much greater problem in the aftermath of Hurricane Floyd and unprecedented flooding in Pitt County. Four programs scheduled for mid-September had to be canceled and we are not sure yet what the rest of the month will be like. If necessary, we will reschedule these at a later date and delay the start of the post-intervention survey (see Appendix B for a complete list of problems with program presentations).

We have two techniques for evaluating immediately the effectiveness of the programs. The team of speakers at each event is asked to complete a form listing the total attendance, questions raised by the audience and problems encountered. Because we learned that some groups did not have operational video equipment, feedback from speakers led us to purchase a portable TV/VCR unit that the speaker can take along to a site. Other comments led us to alert speakers to questions they should be prepared to address as these arise.

We also had each person attending the session complete an evaluation sheet. We asked them to rate the program and speaker and gave them the opportunity to make open-ended comments. Overall, the comments were extremely favorable. Attendees especially liked the fact that the video featured real women from eastern NC and that a speaker from the region directed the presentation. Many also appreciated the emphasis on early detection and were pleased that the video dealt directly with the importance of religion in many women's lives. There were only a few negative comments. Some women did not like the component on religion in the video and some found the video too long. A couple of women were depressed by the case of the young mother with cancer. These comments are summarized in detail in Appendix B in a section titled, "Summary of Comments on Presentation/Evaluation Forms."

The other measure of program effectiveness will come from the post-intervention survey in Year Four of the project.

c.2 television and newspaper advertising campaign

As part of **Task 3**, we continued revision to our public service announcements for television and filmed 12 of these in Los Angeles with several prominent African-American actors and actresses who graciously volunteered their time. These PSAs address the six main barriers to early detection uncovered in our previous research and are framed at different time intervals including 10, 20 and 30-second spots. A video tape including all of these is in the appendix. For **Task 4**, copies of these were sent to all local

television stations, including the NBC, CBS, ABC and FOX affiliates. These PSAs have been shown at various times throughout the intervention period. We have been fortunate that one local station regularly features our PSAs prior to the Oprah Winfrey show that is very popular with women in our county.

As part of **Task 3**, we also developed a series of ads for the local newspaper. These also target our six main barriers to early detection and each is being run on Sunday and Wednesday in sequence in the county's main newspaper, the *Greenville Daily Reflector*. In addition, these ads are being placed in the first annual edition of a new publication, the *Medical and First Aid Handbook: Directory of Medical Professionals in Pitt County*. Copies of these ads are included in Appendix A. In conjunction with **Task 4**, we had a feature on one of our education sessions on the local television news in June of 1999 and one of our lay speakers, a breast cancer survivor, was a guest on a local cable channel interview program. Two county newspapers also did feature stories on our lay speaker's bureau as did the University Health Systems of Eastern North Carolina publication in July of 1999. An announcement of the availability of programs through the speaker's bureau of EC-BCAP has been run twice a week every week in the main newspaper of the county. Copies of all these articles are included in Appendix A. In addition, Dr. Lannin, Dr. Mathews, Mrs. Swanson, and Ms. Best were also interviewed on local television and radio stations about the EC-BCAP intervention initiatives.

The success of these publicity efforts will also be assessed on the post-intervention survey in year four of the project.

c.3. intervention in OB/GYN offices: "Generation to Generation Project"

Our third intervention initiative was a project designed to ask younger women who currently see OB/GYN practitioners in Pitt County to take information about breast cancer home to their older female relatives who may not be under direct medical care. Prior to designing this project, we were fortunate to obtain the assistance of an African American medical student and an African American health education graduate student. The medical student, Ms. Benita Williams, was one of our trained lay speakers. She was selected as one of the East Carolina University School of Medicine's summer scholars. This program is designed to give first year medical students experience in conducting research and to mentor them in the research process. Ms. Williams chose to work with the OB/GYN project as she plans to become an OB/GYN physician. She assisted in analyzing the data from our Time 1 survey (**Task 6**) in order to provide the research rationale for the OB/GYN initiative and in order to help design materials. She then assisted with the design of project materials and the conducting of the intervention itself. She subsequently gave a presentation on the outreach project at the ECU School of Medicine Medical Student Research Day on August 16, 1999 and had her abstract included in the program (copies of her presentation slides and of the program are included in Appendix B).

A member of our advisory board recommended the health education graduate student, Ms. Shantell Carter, and we employed her to assist with the design of the materials for and the implementation of the OB/GYN project. She continues to work with us on this initiative. We are very pleased that an unanticipated but very important

outcome of our project has been the chance to mentor two future African-American health professionals in the need for breast cancer research and education.

The preliminary analysis of our data (see Appendix C) provided strong rationale for the OB/GYN intervention. Among women older than 40 in our pre-intervention survey, only 57% had had a mammogram within the past year. If they reported that their primary physician was an OB/GYN physician, 85% had had a mammogram within the past year compared to 68% for women whose physician was a general internist, 59% for women whose physician was a family doctor, 59% for women whose physician was another "specialist," and only 21% if the woman did not report having a primary physician. Thus, OB/GYN physicians seem to have the most interest in breast cancer screening and are most likely to ensure that their patients get regular mammography.

Unfortunately, only 16% of the women reported that their primary physician was an OB/GYN specialist. However, this was inversely proportional to age. Thirty percent of women under age 40 reported their primary physician to be an OB/GYN physician compared to 13% for women ages 41-65 and only 2% for women over 65. Thus, the findings clearly indicate that although OB/GYN physicians have the greatest interest in breast cancer screening, older patients who are at highest risk for breast cancer are least likely to see an OB/GYN physician. We were very hopeful, therefore, that the OB/GYN practices would encourage their young patients to take educational literature to their older female relatives.

In planning the OB/GYN intervention, we first sent letters and then Dr. Lannin contacted all of the OB/GYN practices of Pitt County by telephone. In the letters we asked if they would be willing to participate and if they could designate a contact person. Eventually, all five group practices, including the Pitt County Health Department, agreed to participate. The students went along with Mrs. Swanson to meet the contact people in each practice in order to explain the project and obtain feedback. It became apparent in the planning process that the materials would need to be self-guided as office staff were extremely busy. Also, in many practices, two hundred or more women were seen a week so we knew that we would need approximately five thousand copies of our educational materials.

As part of **Task 2**, we met as a project team to design the OB/GYN educational materials. We devised a plan that would be self-guided. An informational poster featuring photos of real women in Pitt County was designed for each practice site. The poster announces and explains the project (see Appendix A for a copy). Women coming into the participating practices for appointments would be given a one-page quiz to take while in the waiting room. This quiz (see appendix A) was designed by reference to the type and sequencing of questions to lead women to realize that the risk of breast cancer increases with age, that older women often do not get regular medical care or breast screening, that early detection is the best prevention, and that family members can be very important in encouraging relatives to get mammograms. On the back sheet of the quiz the answers to the questions are given. After completing the quiz, the woman fills out an information sheet which she is then asked to turn in to the receptionist. This sheet (see Appendix A) asks for information about her and whether or not she has any older female relatives *living in Pitt County*. If she answers yes and then says she would be willing to share information on breast cancer with them, the office receptionist hands her a packet for each relative and an instruction sheet.

In designing these packets (see Appendix A for a copy), we had to think of some incentive for participation that could be built into the materials themselves. We thought that a greeting card that could send a message of care and concern to a relative would be such an incentive. We were fortunate to obtain a donation from Hallmark of 5000 of the greeting cards they had designed especially for breast cancer awareness month. Our instruction sheet (appendix A) asks the woman patient to take a card and address it to her relative; to write a message; and to insert the materials from the packet in the card. These materials include the quiz itself, our EC-BCAP brochure and bookmark, and a stamped, addressed evaluation postcard. We encourage the women patients to take these personally to their relatives but indicate that if they do not feel comfortable doing so, they should mail them. The older relative is then asked in the card to read the enclosed materials and fill out and return the evaluation postcard (see Appendix A) to our office. The postcard asks if they read the materials and found them helpful and asks them to check any of several outcome measures that the materials led them to complete.

In conjunction with **Task 4**, we delivered these materials at the beginning of June of 1999 to the participating practice sites (see Appendix B for a list of these), and the OB/GYN intervention will run until the end of October of 1999 or until the materials are depleted, whichever comes first. The health education graduate student and Mrs. Swanson are contacting the participating practices and the health department weekly to monitor progress, troubleshoot problems, and retrieve forms. There have been some initial problems. One practice has been so busy that they were not able to begin and consistently distribute packets. At the health department, the bureaucracy was such that no one assumed personal responsibility for the project. We have decided, therefore, to put one of our project people out to observe one day each week at each site to help them learn the best way to distribute the materials consistently.

The evaluation of this intervention will be four-fold. The medical and health education student participants will write an evaluation of how they think the intervention worked within the practice setting noting the strengths and weaknesses of this type of approach. The returned post cards will provide us with a direct means of evaluating the outcomes of the project. However, because we know that mail survey rates are usually low, we also plan to call back each patient who turned in the information sheet and took packets for relatives to see if she did indeed read the materials and passed the information along to her relatives. Finally, the post-intervention survey will also include questions designed to evaluate the effectiveness of this outreach initiative.

Task 5: Conduct Post-Intervention Survey, Months 37-42

While this task was not projected to be part of the current grant year, we have already begun work in preparation for the upcoming survey. Mrs. Swanson is reviewing the list of previous interviewers and contacting them to see which ones will participate again and to determine our need to recruit additional assistants. A copy of the previous survey has been distributed to the project team, and each member has been asked to review it and make recommendations about items that should be retained and those that can be eliminated. A project team meeting in September will be devoted to designing questions to assess the impact of the specific interventions discussed above so that the

draft survey form can be typed and designed during October in preparation for beginning the survey in November of 1999.

Task 6: Analyze Results and Report Findings

Again, this task was not part of the current project period. However, we continue to do ongoing analyses of the results in order to justify and guide the direction of our interventions (see section c.3. above), in order to prepare publications, and in order to determine the usefulness of certain questions and make decisions about whether or not to retain them in the post intervention survey.

One example of our review of the questions concerns those regarding religiosity. The data provide an opportunity to explore in detail the role of religious belief in preventive health behavior. We have identified three dimensions of religious belief that pertain to preventive health practices. The first is faith that God will work through doctors and guide medical treatment to promote healing. This dimension represents an aspect of religiosity that combines both belief in the effectiveness of medical treatment as well as belief that God works in concert with medical practitioners to promote healing. An example of the 7 items in this dimension is "God would work through doctors to cure a breast cancer."

The second dimension of religious belief is that God or faith in God alone will cure disease and illness, exclusive of medical care. This dimension presents a challenge for intervention to promote change among people who adhere to the belief that medical care is not necessary. One of the three items in this dimension of religious belief is, "God alone would cure breast cancer without help from doctors."

The third dimension represents people who do not believe that religion plays a part in curing illness or disease. An example of the 3 items in this dimension is, "Doctors alone would cure it (a breast cancer)."

In the post-intervention interview, we will add more items to better measure and understand belief that religious faith alone will cure cancer in the absence of doctors or medical care and belief that religion plays no part at all in breast cancer treatment. Since religious belief is very strong in the study region and it plays an important part in the lives of a significant number of people, we are encouraged by our finding that religion is relevant for preventive health behavior in multiple ways. A manuscript outlining the different ways that religion influences belief in the effectiveness of cancer treatment is in preparation.

Potential Problems with Task 6 in Year 4

The severe flooding of Pitt County (our intervention county) in the wake of Hurricane Floyd may lead to some serious potential difficulties for beginning the post-intervention survey in November of Year 4 (1999-2000). It is estimated that several thousand Pitt County residents have lost their homes, and countless others have suffered major trauma. The northern sections of the county are still impassable, and children have yet to return to school two weeks after the storm. Many roads and bridges have suffered extensive damage. Our control county (Wilson County) was also affected by flooding although not to the extent of Pitt.

We will need to assess first the degree to which our interviewers have been affected personally by this disaster in order to determine our need to recruit additional personnel. We will also need to monitor flood recovery and possibly revise our timetable for the implementation of the survey. Our research plan calls for us to recontact the 1200 women surveyed initially in Pitt and Wilson Counties. Their participation is crucial if we are to assess the effectiveness of our intervention programs. If these women are unable or unwilling to participate by November, we will need to delay the beginning of the survey period and push back our timetable for data analysis. One possible revision to the workplan that we are considering would be to delay the beginning of the post-intervention survey until January of 2000 and to ask for a nonfunded extension of the project from the ending date of August 31, 2000 until December 31, 2000. This revised timetable would give us adequate time within the funded grant period to complete data collection and entry, and the unfunded extension would give us time to fully analyze and write reports on those data. At this point, we are unable to make a concrete decision about the timetable until we see how extensive a period of recovery from the flooding is needed in the county. However, should we decide that a delay is necessary, we would use the intervening two months to continue our intervention programs, especially our OB/GYN initiative.

Key Research Accomplishments:

- Completed almost 1200 surveys
- Developed educational video
- Developed public service announcements
- Developed educational pamphlets and bookmark
- Conducted educational programs in churches, work sites, organizations
- Conducted intervention through OB/GYN offices

Reportable Outcomes:

Presentations and Publications:

“Socioeconomic and Cultural Influences on Racial Differences in Late Stage Presentation,” for the Breast Cancer Symposium, ECU School of Medicine, Greenville, NC, December 3, 1998.

“Generation to Generation: An Intervention Enlisting Younger Women to Teach Older Family Members about Breast Cancer,” for the ECU School of Medicine Medical Student Research Day, ECU School of Medicine, Greenville, NC, August 16, 1999.

“Breast Cancer: Where Are We Now?,” for The Women’s Health Conference, Ramada Plaza Hotel, Greenville, NC, October 8, 1999.

Negotiating Cultural Consensus in a Breast Cancer Self-help Group, *Medical Anthropology Quarterly*, October, 1999.

Who Gets the Message about Breast Cancer Screening? Race, Socioeconomic Status, and Physician Recommendation for Mammography. *Journal of General Internal Medicine* submitted.

Consultantship:

“Evaluating the Effectiveness of Messages to Improve Breast Cancer Screening Rates among Different Ethnic Groups in Rural Georgia,” consultant (Holly F. Mathews), funded by USRMADC for Morehouse School of Medicine, Atlanta, GA, 1997-present.

Conclusions:

We have developed culturally sensitive educational materials and have presented our educational program to over 1000 people in Pitt County. Through the use of the video and brochures in addition to the public service announcements, we have been educating women about the importance of screening as well as the risk factors and symptoms of breast cancer. We hope these efforts will help lead women to seek immediate medical attention if they develop any symptoms, thus leading to diagnosis at an earlier, more treatable stage.

The OB/GYN component is a unique attempt to reach women over age 50 through their younger female relatives. This older group is facing greater risk for breast cancer yet may not be receiving regular breast screening.

Our ultimate goal is to reduce breast cancer mortality. The educational presentations and OB/GYN component have great potential to attain this goal both in eastern North Carolina and other areas where psychosocial beliefs may delay breast cancer presentation.

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Clear & Simple: Developing Effective Print Materials for Low-Literate Readers. National Institutes of Health. National Cancer Institute. 1990-1991.

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Appendices

Appendix A

EC-BCAP invitation
Kick-off agenda
Bookmark
Brochures
Newspaper articles about kick-off
Breast Cancer Symposium program, NC chapter, American College of Surgeons
Speaker's bureau training manual
Speaker's forms and evaluation form
List of scriptures
Advertisements and publicity articles
Women's Health Conference program
OB/GYN letter
Poster
Generation to Generation quiz and information sheet
Generation to Generation packet

Appendix B

List of speaker's bureau participants
Monthly list of programs
Problems encountered with presentations
Summary of comments on evaluation forms
Quotations from evaluation forms
Medical student research abstract and slides

Appendix C

Data tables

Appendix A

EAST CAROLINA
BREAST CANCER AWARENESS PROGRAM
KICK-OFF RECEPTION

GREENVILLE HILTON
OCTOBER 6, 1998
6:30 PM

Introductory Remarks	Donald Lannin, MD
Welcome	Mayor Nancy Jenkins
Project Goals and Plans	Dr. Lannin
Planning Committee	
Holly Mathews, Jim Mitchell, Melvin Swanson, Frances Swanson,	
Kim Best, Linda Pololi, Lorraine Tafra, Sharon Edwards, Jon Newton,	
Anup Patel	
Advisory Board	
Ask those present to stand	
Video Presentation: <i>To Live On</i>	
Introduction of Patients	
Mary Garris, Richardine Faison, Tina Young, Rebecca Prigeon,	
Alice Jones, Mazie Reynolds (moved to Texas)	
Recognition of Green Family	
Mark Green, Marian Carson, Beth Everett	
Introduction of Filmmaker	
Fleming (Tex) Fuller	
Special Thanks	
Bruce Schroeder, MD and Staff of Eastern Radiologists	
Ceylon Rowland, MD and Staff of Women's Health Center	
Rev. Rosa Lee Norfleet	
Keynote Speaker	Sylvia Dunnivant
Questions/Comments	
Closing Remarks	Chaplain Randy Curtis

Breast cancer video filmed at PCMH, local cancer center

■ The video features six Eastern North Carolina women and their experiences with breast cancer.

By Jeannine M. Hutson
Special to The Daily Reflector
10-5-98

For the six eastern North Carolina women featured in the breast cancer awareness video "To Live On," cancer is a personal disease. Their stories will be premiered Tuesday evening during the Eastern Carolina Breast Cancer Awareness Program kickoff reception at the Greenville Hilton Inn. Five are breast cancer survivors; the sixth is shown receiving her early mammogram which detected cancer.

At the kickoff reception, Sylvia Unnivant, author of "Celebrating the African-American Woman: A Book About Breast Cancer," will talk about the experiences of African-American women with the disease.

The evening marks the start of a long educational drive by the Eastern Carolina Breast Cancer Awareness Program, whose members include faculty and staff from Leo W. Jenkins Cancer Center and East Carolina University as well as community members from the county. The goal of the program is to better educate Pitt County men about breast cancer and

negate myths associated with the disease. In the 27-minute video, the women talk about their fears of breast cancer and how they overcame them in the process of seeking treatment.

Shock was the first reaction of health-conscious Mary Garriss of Beaufort, who has had a mammogram religiously as part of her yearly physical exam, when she was diagnosed with breast cancer in July 1996, while "To Live On" was being filmed at the Leo W. Jenkins Cancer Center and Pitt County Memorial Hospital.

"I didn't think I was a candidate, but everybody is a candidate (for breast cancer)," she said. "When they told me, I thought I would just die the next day. I went and got my will out of the safe deposit box and updated it."

But she didn't die that summer. Mrs. Garriss had a mastectomy and chemotherapy follow-up treatment and says she is "doing fine" today.

University Health Systems of Eastern Carolina includes Pitt County Memorial Hospital, East Carolina University School of Medicine, private practice physicians and other health affiliates.

Mrs. Garriss, 72, said she agreed to have the film crew document her surgery at PCMH to educate other women.

"I hope (the video) will have an

See *CANCER*, B3

CANCER

Video features local
breast cancer patients

Continued from B1

impact on the people who see it and know it's not a death sentence. With a good attitude and the backing of family and their support, you can make it," she said. "I look back and say it's not that bad."

Dr. Donald R. Lannan, director of the Leo W. Jenkins Cancer Center at University Health Systems of Eastern Carolina and a professor of surgery at the ECU School of Medicine, said he hopes more education on the grass roots level will result in women going to see their physician in the earliest stages of cancer.

"Our ultimate goal is to reduce the incidence of late-stage breast cancer," he said. "We want women to present with smaller cancers that are more curable. We hope this video will make women much more aware of the disease and realize that breast cancer is not a death sentence. It is a very curable disease when presented early to a physician."

A speaker's bureau has been formed of ECU breast cancer experts and researchers, who will present a program featuring the video and discussion to Pitt County civic, church and recreational groups.

In a recent seven-month survey of 1,200 women in Pitt and Wilson counties, ECU researchers found that 43 percent of African-American women and 45 percent of white women in Pitt County said that their regular physician has never talked with them about their risk for

"We hope this video will make women much more aware of the disease and realize that breast cancer is not a death sentence. It is a very curable disease when presented early to a physician."

Dr. Donald R. Lannan
director of the Leo W. Jenkins Cancer Center

developing breast cancer.

Because of this finding, the East Carolina Breast Cancer Awareness Program will work with area family physicians to make sure that they are up-to-date about breast cancer and to encourage them to talk with their female patients about their risks for developing the disease.

The program hopes that through educational efforts women, especially blacks, will be better able to make educated choices when breast lumps are detected. Socioeconomic factors combined with cultural beliefs and attitudes play a role in the delayed diagnosis of breast cancer in African-American women, according to an eight-year study led by Lannan.

The study was published in the June 10 issue of the Journal of the American Medical Association.

Researching breast cancer, filming the video, and producing educational materials have been funded by grants from the American Cancer Society and the Department of Defense. The video was produced by Fleming Fuller Productions of Kingston.

"Part of our project is to reduce certain fears, such as that your husband or boyfriend is going to leave you if you're diagnosed with breast cancer. Another fear is that medical treatment, for breast cancer is not compatible with religious

beliefs. Both of these fears have not shown to be true," Lannan said.

Breast cancer survivor Mrs. Garriss was a little worried about her husband's reaction to her diagnosis. He was, in fact, her biggest supporter, she said. "He loved my bald head. He'd come by and rub it," she said with a laugh. "Of course, all of my hair grew back after chemotherapy."

Greenville's Tina Young also had the support of her husband during her diagnosis of breast cancer in July 1996 and its recurrence in June, three months after the birth of her second child.

"I'm thinking that since we caught it early, the chemotherapy will work," she said.

Mrs. Young, like many breast cancer patients, doesn't have a history of cancer in her family. She hopes that "To Live On" will educate women about the need to have mammograms yearly and to see a doctor immediately if they find a lump in their breast.

Early detection and a positive attitude are two factors that Mrs. Young feels she has on her side during this latest bout with cancer. "I feel like staying positive last time helped me," she said. "And I've got three good reasons, my husband and my children, why to try and beat it again."

AWARENESS

Regular exams help
stave off disease

Continued from B1

director of the Cancer Center.

Patients who have their breast cancer detected in its earliest stage have a 90 percent chance for survival, compared to only a 25 percent chance in the latest stage.

Unfortunately, Lannin said, women in eastern North Carolina have historically had their disease diagnosed later than women nationally. And black women here are more likely than their white counterparts to delay detection.

"African American women have about the same chance as white women of getting the cancer, but we know that they're more likely to die than white women," he said.

A 10-year study done by Lannin and his colleagues showed that cultural beliefs sometimes kept black women from seeking care.

Some of the reasons black women gave for not seeking early medical attention included believing that exposing their tumors to air such as during surgery, would cause them to spread.

"This is something that isn't true. The best treatment of a breast cancer is to operate on it early and remove it," Lannin said.

Rebecca Prigson, a 43-year-old

black woman featured in the video, said a lump had covered half her breast before she sought medical attention.

Journalist Sylvia Dunnivant, who was the guest speaker for Tuesday's event, was inspired to write her book "Celebrating Life: African-American Women Speak Out About Breast Cancer" after her aunt died of the disease.

"I realized we were dealing with this disease in silence. We had this false sense of security that this

disease had passed us by," she said.

Ms. Dunnivant encouraged all women to make their health and breast exams a priority. "We need to take care of our personal health. We have one body, it's our holy temple, and we need to govern it accordingly."

Breast cancer is the most common type of cancer in women and affects 1 in 8.

"That's the size of a major city, the number of women that get breast cancer," Lannin said.

Chris Cummins/The Daily Reflector
DERRICK HARRIS SLICES some turkey for Marian Carson at the East Carolina Breast Cancer Kickoff at the Hilton Inn. October is National Breast Cancer Awareness Month.

Testimony of survival urges awareness

■ More than 200 hear stories of hope at the kickoff event for East Carolina's Breast Cancer Awareness Month.

By Clejette Pickett

The Daily Reflector

For years, Alice Jones had her annual mammography, and each time the test for breast cancer came out negative.

So when the time came for her and her sister, Margaret Bass, to have the tests done in 1993, Ms. Jones thought she would skip it.

But Ms. Bass, the older of the two siblings, insisted that the two of them go together as they had always done to have the annual exams.

Her insistence paid off. Ms. Jones had the test and found out weeks later she had cancer.

"I never expected to have cancer," she said. "Nobody in my family had ever had cancer. My dad had heart problems, and my mom had kidney problems."

After surgery, chemotherapy and radiation treatment, the 61-year-old Edenton resident fully recovered.

But she knows that if she had not listened to her sister and had her breast examined, she might not be alive.

"I never felt bad," she recalls. "I was just going along with my usual routine."

Ms. Jones is one of five breast cancer survivors featured in a new video to make other women aware of the disease and the importance of routine exams.

"I felt like if I could help anybody go get a mammogram, I would be willing to do the video," she said.

"To Live On," the 27-minute video, premiered before an audience of more than 200 people at the Hilton Inn Tuesday in a event to kickoff the East Carolina Breast Cancer Awareness Program.

The program is sponsored by the Leo W. Jenkins Cancer Center and

East Carolina University.

A speaker's bureau has been formed of ECU breast cancer experts and researchers, who will present a program featuring the video and discussion to Pitt County civic, church and recreational groups.

The video, which features testimonials from each of the survivors, will be the main attraction of the year-long project to get women to seek early detection.

"In terms of making a difference in this disease, the most important thing we can do is catch it while it's early," said Dr. Donald Lannin,

See AWARENESS, B3



**THE EAST CAROLINA
BREAST CANCER AWARENESS
PROGRAM**

**SPEAKER'S BUREAU TRAINING
MANUAL**

*The East Carolina Breast Cancer Awareness Program is affiliated with the Leo W. Jenkins Cancer Center
and East Carolina University*

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Linner W. Griffin

Donna Harris
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Phyllis Horns
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Dorothy Josey
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Sidney Locks
Julius Mallette
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Randy Royal
Ceylon Rowland
Terry Shank
Anna Shappley
Edward Treadwell
Carmen Vincent
Reginald Watson
Scott Wells
David White
Marian Gorham Wilkes

PROJECT GOAL

The major reason that some women in our region have poor survival from breast cancer is that they present with advanced stage disease. Our previous research has indicated two reasons for late stage breast cancer presentation in this population: (1) lack of breast screening including clinical breast exam and mammography, and (2) patient delay due to cultural and psychosocial beliefs. The goal of this project is to develop methods to encourage earlier detection of breast cancer in our area. A community-wide intervention is scheduled to begin in 1998 and 1999 in an attempt to promote breast screening and alter those cultural beliefs and practices that may cause some women to delay getting treatment. The intervention will utilize educational messages through television, radio, and newspaper; educational programs conducted through local churches, businesses and schools; and a unique program where older women are reached through their younger relatives who are seeing Ob-Gyn physicians.

THE MESSAGE OF EARLY DETECTION

❖ PROBLEMS IN EARLY DETECTION

There has been much research as to why women die from breast cancer. One reason women sometimes die from breast cancer is because they wait too long before going to a doctor after finding a problem with their breast. The number of deaths due to breast cancer could be reduced if women participated in a program of regular breast health screening including monthly breast self examinations, yearly breast examination by a doctor and regular mammography. Education and awareness of breast health is imperative. In order to help women understand the importance of regular breast screening, we must first understand why women wait to take care of their breasts.

Most women know something about breast cancer. They know it can mean the loss of a breast, painful treatment, and possible death. These are the images of breast cancer that first come to mind, and most of us tend to stop our thinking right here. The mere word cancer can elicit a wide range of reactions. It touches our fears, our faith, our sorrow and our anger. Fear is probably the greatest factor when considering why women wait to seek medical attention. We fear what we don't know about breast cancer – possible death, disfigurement, loss of intimacy and support and loss of control over our lives. Gaining accurate information about breast cancer can help us overcome our fears. The more knowledge we possess, the more able we are to make the right choices about our health.

The East Carolina Breast Cancer Awareness Program is a community wide effort to educate women in Pitt County about the importance of screening and to share information that may help dispel fears and beliefs that are keeping women from seeking treatment. Through our research we have discovered 6 topics that we have targeted as teaching points.

SIX MAIN TEACHING POINTS

- ***What you do can make a difference.*** We often feel powerless against a disease that seems to take control over our lives. Cancer at worst can seem like a death sentence and at best it is a frightening inconvenience. Some women believe that once they are diagnosed with cancer their fate has already been predetermined and that treating the cancer through surgery or chemotherapy may be of little relevance. Many years of research and experience have shown that if breast cancer is detected and treated at the earliest possible opportunity, there is a great chance for successful treatment and long term survival. The choices we make about our health and health care do make a difference.
- ***A lump is serious even if it does not hurt.*** Although lumpy breasts may seem normal, a doctor should still check them out. Most of us believe that pain is our first indication that something is wrong with our health. With breast cancer this is not the case. Most early breast cancers do not cause pain. Every lump should be taken seriously and evaluated by a doctor.
- ***Air does not cause cancer to spread.*** Some women believe that having surgery or cutting on a cancer will cause it to spread. We know that removing a malignant tumor or exposing it to air does not cause it to spread. In fact, delay in the removal of cancer most often will result in the further spread of cancer. It is often our fears or our lack of information that cause us to avoid treatment that may very well save our lives. Surgery for treatment of cancer is often the first and best line of defense.
- ***Having breast cancer makes you no less of a woman.*** While the loss of a breast is significant it does not change the fact that we are women. However, as women, we may fear losing our desirability and sexuality, and thus fear the loss of intimacy and support from a significant other, namely our husbands or male partners. When diagnosed with cancer, we need the support of our loved ones but we don't need people who can not support us and will only bring us stress and discouragement. If the fear of losing a partner is keeping us from going to a doctor, we need to have courage to confront that fear by sharing our concerns with our partner and by looking at cancer as a problem to face together.
- ***God works through and with your doctor for healing.*** Many women believe God alone can cure their cancer and that no other treatment is required. We wish to emphasize the healing power of God and the importance of faith in the healing process, but we want to encourage women to seek medical treatment. It is our experience that God works through doctors and other health care professionals to cure breast cancer and other diseases.
- ***Alternative therapies can complement standard medical treatment.*** Some women seek alternative treatments as a replacement to standard medical treatment. We suggest that surgery, chemotherapy and radiation are currently the most effective treatments for cancer. However, we recognize that some nontraditional treatments can aid in the healing process when used in conjunction with traditional western medicine.

ROLES AND RESPONSIBILITIES OF A SPEAKER

- **Be familiar with the purpose and importance of the project so you can answer questions about the project.** Many women may want to know how the project came to be. Be able to explain the purpose of the project in your own words. Refer to the brochures if you are unsure.
- **Know how to confront problems and less-than-ideal circumstances.** Most problems will be minor and can be handled as they occur. For example, should an unexpected emergency (i.e. car problems, etc.) result in the delay or cancellation of a scheduled presentation, be responsible enough to call and inform the contact person. Also, for your benefit, call the contact person 24 hours before the presentation to make sure there have been no changes. More serious problems (i.e. your inability to fulfill your role as a presenter) should be brought to the attention of the project manager, Frances Swanson.
- **Keep what is learned from or about your audience confidential.** Everyone working on this project must maintain confidentiality. All information obtained during the presentation, that concerns the audience or their families, is privileged information. Information should not be shared with your family, friends, or other presenters. The information may only be shared with the project personnel listed on page 2. We expect all presenters to follow this rule.
- **Be attentive to your appearance.** Your appearance is important to a successful presentation. Try to dress in the middle range between very formal and very informal. We want you to be comfortable, but we also want the audience to feel comfortable around you. Dressing too formally (i.e. business suits, etc.) may intimidate some people or make them feel inadequate. Dressing too informally (i.e. jeans, T-shirts, etc.) may offend others or cause them to doubt your professionalism. Find out from your contact person for the group about what you should wear. Also be advised that certain personal habits such as smoking and gum chewing may turn people off. Do not engage in such activities once you arrive at your destination.
- **Put the audience at ease so that they will feel free to ask questions.** The best way to do this is to be prepared for your presentation. Have everything you need and know what you are going to say. If you are unaccustomed to speaking in front of groups, practice what you are going to say in front of a mirror or to a friend. If you are prepared and confident, you will be more relaxed and this will help put your audience at ease. Also, be sure to show a compassionate attitude and an interest in the audience's concerns. Their questions are important to them or they would not be asking them.

GETTING READY FOR THE PRESENTATION

Scheduling a Presentation

A person from the office of the project manager will call you to see if you can do the program. This person will provide you with:

- the name of the group
- contact person
- phone number
- address
- date
- time

If the time is convenient for you, you are to call the contact to confirm the presentation. When speaking with the contact person, ask questions about the group that will help you prepare for your presentation – number of people, age range, setting for meeting, how much time they have allotted for the presentation, etc. You will need to let the contact know what you need for the program, i.e. TV, VCR and any other materials. Also, be sure to call the contact person within 24 hours of the presentation to confirm your plans.

Things to Take to the Presentation

1. Video tape
2. Contact form
3. Schedule form
4. Evaluation forms
5. Interest forms
6. Breast model
7. Beads
8. Pencils
9. Brochures, bookmarks, and shower cards

All of these materials will be provided to you. You will need to check out a “kit” from the office.

PRESENTATION OUTLINE

In order to be sure that there is continuity in the way that the program message is communicated, we would like for everyone to follow the same presentation format. Ideally, there will be an hour for the presentation.

Introduction – 5 to 10 minutes (see sample statement, page 10)

Introduce who you are. You may want to share your profession, why you are a part of the program, and if you are a breast cancer survivor. Then briefly talk about the East Carolina Breast Cancer Awareness Program (ECBCAP) – it's history, research, and goal of increased awareness. You can include some basic statistics about breast cancer and the effectiveness of early detection. Finally, introduce the video that the group is about to see.

Video - *To Live On* – 25 minutes (see summary guide, page 11)

We have provided a guide to the video so that you can familiarize yourself with the women in the video and with some of the key issues that they confront as women with breast cancer. The summary guide may also be used to help with discussion after the video.

Discussion – 20 to 25 minutes (see discussion tips, page 14)

During this time, we want to explore the reactions of the audience to the powerful stories in the video. In doing so, we want to try to touch on the six teaching points (page 6), some of which were directly addressed in the video. During the discussion please cover these areas:

- Reactions to video
- The six teaching points
- Screening guidelines – breast self exams (teach this if requested), clinical exams, mammography and use breast model if women are curious about what lumps may feel like.
- Questions from the audience – answer questions to the best of your ability but don't be afraid to say you don't know the answer. You are not expected to be an expert on breast cancer.

Use the resources provided. Try to empower the women by encouraging them to gather information for themselves and to take action when it comes to their health. Please lead the discussion in a manner that feels comfortable to you and that also seems appropriate for your audience. Be aware of the time during this portion of the presentation. It is easy to get stuck on one specific issue and not have to cover all the bases. Also, we want to be considerate of the audience by being aware of their meeting schedule.

Closing – 5 minutes

Handout the evaluation forms, brochures, bookmarks and shower cards. While they are completing the forms, you may want to take time to answer individual questions. Ask if anyone would like a scheduling form for future presentations to other groups. Be sure to thank them for their time and consideration.

PRESENTATION INTRODUCTORY STATEMENT – SAMPLE

Hello, my name is _____. I am here today/tonight representing the East Carolina Breast Cancer Awareness Program. This program is a joint effort of community members and faculty and physicians at East Carolina University and the Leo W. Jenkins Cancer Center. We are sponsoring a year long educational program in Pitt County to increase awareness of breast cancer and to encourage women to seek early treatment.

Each year, in the United States, about 180,000 women are diagnosed with breast cancer and about 45,000 die from the disease. In Pitt County about 200 new breast cancer patients are seen at the cancer center each year. The important message we want to get out is that breast cancer is very curable if it is caught early. Therefore, we want to encourage women to take responsibility for their health by doing breast self exams, seeing a doctor each year for a clinical breast exam, and by having regular annual mammograms once they reach age 40.

But just having examinations is not enough. We also want to encourage women who find a knot or a lump in their breast to see a doctor immediately. The sooner a cancer is found the better the chances of a cure.

This message is especially important here in eastern North Carolina because we have a high proportion of women who wait to seek treatment until they have large breast lumps which are harder to cure.
[Show and explain beads.]

Faculty at the Leo W. Jenkins Cancer Center did a five year study of all women who came in for treatment. They tried to discover the reasons why women sometimes delayed seeking treatment for breast cancer. They found that some women lack the money or insurance to get regular breast screening. Others did not know that they needed regular breast screening or how to get it. But most important of all the barriers were the fears many women had about cancer and about how the people significant in their lives would react to their cancer.

The film that you are about to see tells the story of six women from eastern North Carolina who came to the Leo W. Jenkins Cancer Center for treatment of their breast cancer. These women talk, in their own words, about their fears of cancer and how they overcame them. We think that their stories are inspirational and can help us all to think about what we might do in similar circumstances.

I will begin tonight by showing the video and then leading this group in a discussion about some of the fears and concerns these women expressed and about how they overcame them. Then we will have time for your questions.

SUMMARY GUIDE TO VIDEO – *TO LIVE ON*

This video was made with actual patients seen at the Leo W. Jenkins Cancer Center in Greenville, NC. The stories of four women are featured in detail as they go through the process of diagnosis and treatment. Two other women appear briefly discussing the importance of mammography. This guide summarizes the stories of each woman in the film, the particular fears and concerns each raised and some of the ways these were handled.

MAZIE REYNOLDS, age 60, African-American, Wilson, NC. Mazie felt a lump in her breast and then went to a doctor who ordered a mammogram. After having mammography, she waited a while before seeking further treatment because of her fear.

Specific Fears/Concerns

1. ***Fear of cancer diagnosis/fear of cancer*** – These fears caused her to wait before seeking medical attention. She said, “Fear took hold of me,” and “I was down in my spirit.”
2. ***Shame and secrecy/why did this happen to me?*** – Cancer is like a secret that sometimes makes you feel ashamed. You wonder why is this happening to me.
3. ***Fear of chemotherapy*** – Mazie had heard the horror stories of chemotherapy but she didn’t really know what to expect.
4. ***Concern about intimacy and support*** – She said, “Losing a breast is a test. You find out if he can take it.”

Strategies/Resolutions

1. ***Face facts and fears by going to a doctor for help*** – Once she went to the doctor she realized she was getting the help she needed and her fears were eased. She says that women need to know that the doctor is not going to hurt you; cancer is what’s hurting you. The doctor is there to help so don’t wait around. Don’t let fear keep you from getting the help you need.
2. ***Realize the cancer can happen to anyone*** – Mazie was able to overcome her shame by sharing her story. When you reach out for help people can surprise you and you find out you are not alone. Don’t hesitate to lean on family and friends for support.
3. ***She found out chemotherapy was not as bad as she thought*** – Mazie realized that taking chemotherapy was a way to help save her life. “It’s your life,” and you have to do whatever it takes. For her the experience of chemotherapy was not nearly as bad as she thought it would be.
4. ***“She is no less a woman. She is my woman”*** – This is what Mazie’s husband, Joseph, says. He is a great support to her. He loves her and makes love to her.

Joseph is a good example of a supportive and loving husband. He wants to help her in any way he can. He reminds her that after 43 years of marriage they are a part of each other and they will face the cancer together as a team.

TINA YOUNG, age 31, white, Greenville, NC. Tina began doing breast self exams and found a lump while in the shower. It was a large tumor that had invaded over half of her breast. She went to the doctor right away and they began chemotherapy followed by a mastectomy.

Fears/Concerns

1. *Cancer is a scary word.*
2. *At her young age she had not thought about breast cancer.*
3. *Fear of surgery* – She hopes they get all of the cancer so she won't have to go through it again.
4. *Concern about losing her hair with chemotherapy.*
5. *Concern about the impact of cancer on her family* – She was worried about her young daughter seeing her so sick.
6. *Fear of losing a breast/loss of intimacy and support* – Like most women she wanted to know whether she would still be desirable to her husband.

Strategies/Resolutions

1. *Faced fear of cancer head on* -- She went to the doctor and began treatment.
2. *Realized that cancer can happen at any age.*
3. *Agreed to surgery for the sake of her family.*
4. *Shaved her head* – Tina took control and cut her hair off because it would be easier losing it all at once than watching it fall out slowly. She joked with her daughter about being bald.
5. *Relies on support from her family* – By sharing the burden of cancer with her family she receives their love and support especially that of her daughter and husband.
6. *"I would rather have you than your breast"* – her husband's attitude helps her get past her fears. She says, "If they love you, they will stay; they love you no matter what you look like."

MARY GARRIS, age 71, white, Beaufort, NC. She accidentally felt the lump but decided to wait a while until her regular checkup before doing anything about it. She had a mastectomy.

Fears/Concerns

1. *Fear of finding out she had cancer* – Again we see how the fear of having cancer can be paralyzing.
2. *Shame of having cancer* – Some people may think you "caught" cancer by being somewhere you shouldn't have been or by behaving in a way you shouldn't have.
3. *Fear of surgery.*

Strategies/Resolutions

1. *Relied on her faith in God and in the doctors* – she faced her fears through her faith.
2. *Serenity Prayer* – She realizes that cancer just happens to people and it is out of her control. She prays for the wisdom and strength to control what she can and to let go of worrying about what she can not. She also relies on her husband and family for strength and support.
3. *"Don't let cancer get a hold of you, you get a hold of it"* – The decision to have surgery and the treatment she needs is easier when she realizes that she has a life to live and the importance of never giving up.

REBECCA PRIGEON, age 41, African-American, Grimesland, NC. Rebecca had an advanced cancer two years prior to the making of this video. She had a mastectomy and reconstruction but did not complete chemotherapy. In the video, she learns that she has had a recurrence in the reconstructed breast. The first thing she does is go to the Lord in prayer and then to the doctors.

Fears/Concerns

1. ***Fear of cancer.***
2. ***Relationship with God*** – She wants to have a right relationship with God and to ensure God's protection over her.

Strategies/Resolutions

1. ***Shares her fear with her community*** – Rebecca relies on the support of her minister and her church family who pray for her and encourage her to do what the doctors advise.
2. ***Seeks guidance from her faith and her spirituality*** – Through prayer and consultation with her pastor, she realizes that she has the strength through her relationship with God to go through the surgery and chemotherapy.

REV. ROSA LEE NORFLEET, Rebecca's pastor, is a key support for Rebecca. Rev. Norfleet let's her know that God and her church are with her. Rebecca shows some hesitancy to receive medical treatment because she feels God alone will heal her. She gives the rationale for how God and the medical community can work together when she tells Rebecca she believes God will guide the doctors and show them what to do in surgery. She urges Rebecca to believe in what the doctors and God can do for her and that she will emerge victorious.

RICHARDINE FAISON, age 81, African-American, Greenville, NC. Shown having her first mammogram and clinical breast exam. She is concerned that time is catching up with her and that she needs to know more about the risks of breast cancer. She takes action and shows us that one is never too old to start proper breast health screening.

ALICE JONES, age 59, white, Edenton, NC. She shares the story of her sister making her get a mammogram. Alice feels that it costs too much money and takes too much time to come to Greenville every year for a mammogram. Her older sister tells that it is her life she is watching out for and she better go do it. Through the mammography, Alice discovers she has breast cancer.

TIPS FOR LEADING GROUP DISCUSSION

Goals for Discussion Session: After the video, we want to have a period of time for group discussion. We want to use this time to explore the reactions of audience members to the powerful stories in the video and the feelings that these stories evoke. In doing so, we want to try to touch on the six teaching points highlighted in this program. We also want to share information about breast cancer screening guidelines. Finally, we want to allow time to discuss any specific questions that the audience may have about the film or about breast cancer.

Use of the Six Teaching Points Guide: The teaching points list can serve as a guide to issues that we would like to see covered in the small group discussion period. The audience members will raise many of these points, but if one or two are not mentioned in spontaneous discussion, then we would ask that you try and bring them up for discussion.

Example of how to cover a teaching point: For example, if no one brings up the teaching point about the belief that air causes cancer to spread (a belief not addressed directly in the video), then you might do so at an appropriate point during the discussion. You might say, for example, "Some of the other women in our breast cancer study told us that they were afraid of having surgery because they have always heard that air getting to a cancer will make it spread." Have you ever heard of this belief? What do you think about it?

Strategies for Initiating Discussion after the Video

Remember, after the video ends, allow audience members a few seconds to reorient themselves to the lights and the room before beginning discussion. Because we want to begin with a discussion of people's responses to the fears, beliefs, and emotions raised in the film, we need to think about how to best do that. Asking too general a question, like "how did you like the film" or "any thoughts on the film" will cause people to respond by saying they really liked it, or it was good, etc. Listed below are some possible ways to move the group into a deeper level of discussion prior to a more technical question/answer period.

Strategy 1: Prior to the viewing of the film, pass out 3x5 index cards to audience members. Ask each person to list one fear or concern that they have about breast cancer on the card. Alternately, you might ask them to write down what comes into their minds when they hear the words, breast cancer. Collect these cards. After the video, you can go through a few of the cards, mentioning these fears and concerns and using them as a springboard to discuss similar issues raised in the video.

Strategy 2: This is similar to strategy 1 only you would pass out 3x5 cards after the video and ask audience members to write down the one fear that the women had that most struck them in the video and then you could discuss them. (You could also use a chalk or white board instead of cards for strategies 1 and 2.)

Strategy 3: We have prepared a detailed guide to the characters in the video and the main fears and strategies to overcome the fears associated with each. You might begin the discussion by asking audience members to discuss one of these characters. For example, you might say, "Do you remember Mazie, the first woman who spoke in the video? She and her husband discuss a number of fears that she had to face when diagnosed. What were some of the fears she mentioned? What did she and her husband do to handle them? Do you think this would ever be a problem for you?"

Strategy 4: You might begin discussion by asking the audience members if they could see themselves or any of their own beliefs and fear in that film. Then you might ask what they think their first response might be if they found a breast lump and how they would handle it.

Reminders about Leading a Good Discussion:

- 1) Don't be afraid of silence. It is okay to have a little silence; don't rush to fill it. People may be thinking of what they want to say and eventually, since nature abhors a vacuum, someone will speak.
- 2) Don't feel like you have to have all the answers. People may ask you what you think about a particular belief or issue. You may wish to answer, but is okay to say, "I don't know" or "I'm not sure" and then turn it back to the audience by asking others what they think.
- 3) Remember to refer back to the main messages of the teaching points when appropriate. For example, if someone tells a story about a friend who used an alternative remedy for breast cancer, use that opportunity to reiterate that while many alternative remedies may work, we believe that they are not a substitute for biomedical treatments which still offer the best chance for treatment of breast cancer.
- 4) When people begin to ask informational questions, the majority will revolve around screening guidelines, the appropriate practice of breast self exam (BSE), risk factors, and hormone replacement therapy. The appendix of this manual provides specific information but do not feel obligated to give an answer to every question. You might just remind the audience that there is divided opinion on some of these matters and that specific questions are best referred to their physician.

Review and Wrap-Up

We would like for you to wrap-up the small group discussion by reviewing the six teaching points that are the messages we would like them to take from the program, and then we would like for you to review the screening guidelines for breast cancer. You might end by offering women who are interested the opportunity to use the breast model to practice BSE after the session. Be sure to thank them for coming and ask them to fill out the evaluation sheets.

WOMEN AND BREAST CANCER

❖ INCIDENCE

Breast cancer is the most frequently occurring cancer in women, both in North Carolina and the United States. It is also the second leading cause of cancer death. There are about 180,000 new breast cancer cases diagnosed in the United States each year. Each year approximately 45,000 women die from breast cancer.

Facts about Breast Cancer

- Approximately one in eight women or 12.5% will get breast cancer sometime during her life.
- Eighty percent of women who develop breast cancer have no family history of the disease.
- Although the risks of getting breast cancer is about the same for white women and African American women, more African American die from breast cancer.
- A woman's risk of breast cancer starts at about age 30 and increases with age.
- About 78% of breast cancers occur in women over age 50 and over 50% in women over age 65.
- About 200 new cases of breast cancer are treated each year at the Leo W. Jenkins Cancer Center.

❖ WHO'S AT RISK?

Every woman is at risk. The possibility exists that a woman may get breast cancer at any time during her life. As a woman ages, her chances of getting breast cancer increase. Of the cases of breast cancer diagnosed every year, 70% of the patients have no specific risk factors. Therefore having no risk factors should not give you a false sense of security and cause you to ignore possible warning signs.

Primary Risk factors:

- Age
- Having a family history
- Starting menstruation before age 12
- Having your first child after age 30
- Never having a child
- Beginning menopause after age 55
- Past history of breast cancer

Secondary Risk Factors:

- Long-term use of estrogen replacement therapy or use of the birth control pill
- Benign breast disease history
- Alcohol use

Factors being researched:

- High fat diet
- Excess weight
- Environmental factors

❖ WARNING SIGNALS

Early breast cancer usually does not cause any pain. The first signs of breast cancer can go unnoticed. Most breast changes are not cancer but a woman should see a doctor to be sure especially if they persist.

Some things to watch for:

- A lump or thickening in or near the breast or underarm area
- A change in the size or shape of the breast
- A discharge from the nipple
- Nipple inversion
- A change in the color or feel of the skin of the breast, areola, or nipple
- A lump or other change found during BSE
- Skin dimpling or scaling
- Unilateral changes or changes in only one breast

❖ BREAST CANCER SCREENING

The key to finding breast cancer early is routine screening. Screening is used to look for cancer before there are symptoms of the disease. Breast cancer is 90% curable when found in its earliest stages through screening. There are three methods of breast cancer screening which need to be stressed to all women: **mammography, clinical breast exam, and breast self-exam.**

Screening Recommendations




<u>Test:</u>	<u>Age:</u>	<u>Frequency:</u>
Mammography	40	Every year
Clinical Breast Exam (CBE)	20-39	Every 1-3 years
	40 and over	Every year
Breast Self-Exam (BSE)	20 and over	Monthly

Mammography

A **mammogram** is a x-ray picture of the breast taken by a special machine. Mammography is the most effective ways to detect early stage breast cancer. Research shows that the mortality rate would decrease by 30% if every woman in need of a mammogram had one. Mammograms can detect breast cancer up to two years before it can be seen or felt. The American Cancer Society recommends yearly mammograms for all women over the age of forty. There are two types of mammograms: **screening** and **diagnostic**.

Screening mammograms are used to detect unsuspected breast cancer at an early stage in a person with no symptoms. This determines whether there is either a low or high probability of breast cancer. When cancer is found early, more treatment options are available and the chance of survival is greater.

Diagnostic mammograms are used to evaluate a patient with a breast mass, other signs or symptoms, an abnormal or questionable screening mammogram, or augmented or reconstructed breasts. This usually correlates with physical findings and symptoms.

A Mammogram Can Find A Lump When It Is Still Small.		
Average size of lumps found by regular breast self-exams	Average size of lumps found by first mammogram	Average size of lumps found by getting regular mammograms
		

Getting a mammogram is a very simple procedure. A mammography technician positions each breast, one at a time, on a small platform. A device called a paddle is lowered on the breast and then compresses the breast. Two pictures of the breast are now taken. Another view from the side of the breast is also taken. There will be some pressure on the breast when the paddle is lowered but it is important to get a clear picture of the breast. Some women say that this pressure can be painful, but most women say that mammograms don't hurt.

Clinical Breast Exam (CBE)

A clinical breast exam is a physical breast exam performed by a doctor or nurse. Regular clinical breast exams are an important part of breast cancer screening. When doing a CBE properly, a physician or nurse may be able to find cancers that a woman may not find herself. CBE may also help detect cancers missed by mammography. Some breast changes, including lumps or knots, that can be felt may not be seen on a mammogram. All women should have a CBE every 1 to 3 years and it can be scheduled with your regular check-up. Clinical breast exams can be very effective in finding breast cancer early if they are performed thoroughly. To ensure you are receiving a thorough exam, make sure the practitioner or nurse:

- Palpates both breasts completely (presses into each part of the breast with the pad of the fingers)
- Examines near the collar bone and the armpit area
- Inspects the breasts and asks you to move your arms to make sure there is no dimpling.

Breast Self-Exams (BSE)

Women of all ages should examine their breasts once a month. The most important part of examining your breasts is to become familiar with what is normal for you, so that a change or problem can be found. Women who perform breast exams are more likely to find lumps that are usually smaller than those found by women who don't. Like clinical breast exams, a breast self-exam needs to be done thoroughly. A woman should look for a lump or any unusual thickening that feels different from the rest of her breast. It is important to know the proper techniques to do a thorough breast self-exam.

BREAST SELF-EXAM GUIDE

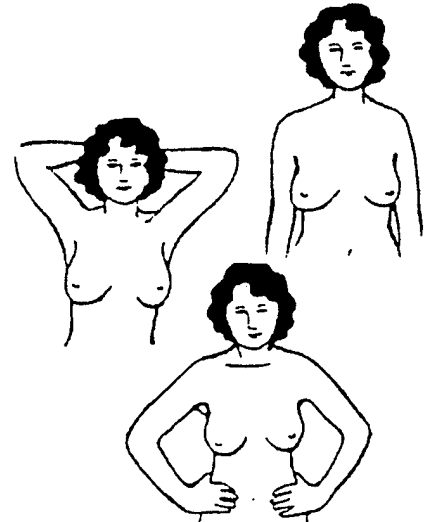
It is best to check your breasts at the same time of each month. The best time is 2-3 days after your period ends. If you are not having periods, pick a day in the month, like the first day of the month, to examine your breasts.

❖ Looking in the mirror for changes

Without wearing a shirt or bra, stand in front of a mirror with your arms at your side. Look for wetness from your nipples and for skin on your breasts which looks wrinkled or flaky.

Next hold your hands behind your head and press your hands forward. Look for any change in the shape of your breasts.

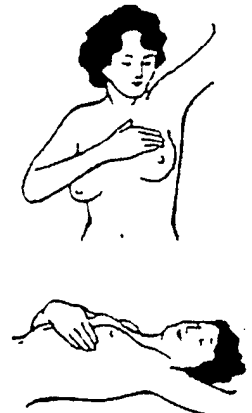
Press your hands on your hips. Bend a little forward and pull your shoulders and elbows forward. Again look for any changes in your breasts.



❖ Feeling for lumps

Raise your left arm. Beginning at the outer part of your breast, feel your breasts firmly with 3 to 4 fingers. Press on your breast with the flat part of your fingers and move in small circles. Move around the entire breast toward the nipple. Also feel the area between the breast and underarm and the underarm itself. Raise your right arm and do the same to the other breast.

Lie down flat on your back with your left arm over your head. Put a pillow under your left shoulder. Feel your breast and underarm the same way you did before. Switch arms and do the same.



❖ Check for nipple discharge

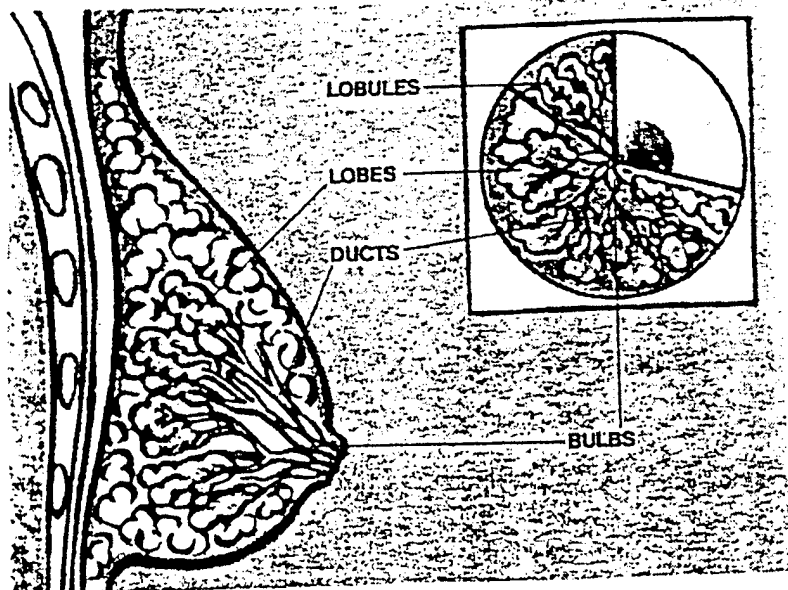
Gently squeeze each nipple to see if anything comes out.



DIAGNOSING BREAST CANCER

❖ BREAST TISSUE

Each breast has 15 to 20 sections, called lobes, each with many smaller lobules. The lobules end in dozens of tiny bulbs that can produce milk. Thin tubes called ducts link all the lobes, lobules, and bulbs. These ducts lead to the nipple in the center of a dark area of skin called areola. Fat fills the spaces between lobules and ducts. There are no muscles in the breasts, but muscles lie under each breast and cover the ribs.



❖ BREAST LUMPS AND OTHER CHANGES

The normal features of the breast can often make them feel lumpy. In addition, from the time a girl begins her period, her breasts undergo regular changes each month. Nearly all breasts develop some lasting changes, beginning when the woman is about 30. About half of all women will experience symptoms such as lumps, pain, or nipple discharge. These symptoms usually disappear with menopause.

❖ BENIGN LUMPS

There are also common benign (non-cancerous) lumps and other changes that occur in the breast. A lump or change in the breast is often not cancer. About 80% of all breast lumps that are tested turn out not to be cancer. The most common are fibrocystic changes, fibroadenomas, cysts, and nipple discharge.

Generalized Breast Lumpiness

Generalized breast lumpiness is also known as "fibrocystic" changes. It often feels like a "ropy" or "granular" area around the nipple, areola, or upper outer breast. This lumpiness shows up most near middle age because milk-producing tissue recedes and is replaced by softer, fattier tissues. It also occurs during menstruation because extra fluid collects in the breast tissue. The breasts can also feel lumpy during pregnancy, when the milk-producing bulbs swell.

Cysts

Cysts are fluid-filled sacs. They occur most often in women 35 to 50 years of age, and they often enlarge and become tender and painful just before the menstrual period. They are usually found in both breasts. Cysts are often found on ultrasound and are usually treated by drawing the fluid out with a needle in a procedure called fine needle aspiration.

Fibroadenomas

Fibroadenomas are lumps that feel rubbery and can easily be moved around. They are usually painless and found by the women themselves. These are the most common types of lumps in women in their teens and early twenties, and occur more often in African American women. Fibroadenomas look benign on mammograms and are sometimes diagnosed with fine needle aspiration. Doctors often remove them because they can enlarge.

Nipple Discharge

Since the breast is a gland, secretions from the nipple of a mature woman are not unusual. Discharge comes in a variety of colors and textures. Discharge may be caused by infection or inflammation of the breast. Keeping the nipple clean or the use of antibiotics treats benign sticky discharges.

Other Benign Conditions

There are a variety of other conditions that may be diagnosed as benign. These conditions are: fat necrosis, sclerosing adenosis, intraductal papilloma, mammary duct ectasia, and mastitis. They are usually treatable with surgery or antibiotics.

❖ CHECKING FOR CANCER

If you find a lump in your breast, make sure you call your doctor to see if he would like to check it out. The doctor can diagnose the problem in three ways: clinical evaluation, aspiration, or biopsy.

Clinical Evaluation

In a clinical evaluation the doctor will carefully examine your breasts and probably schedule you for a mammogram. Through a CBE, he will determine the location and size of the lump. After he receives the mammogram report, he will decide whether there needs to be any further tests.

Aspiration

If the doctor suspects the lump to be a cyst, he will do an aspiration. Aspiration uses a thin needle and is usually not painful. The needle will draw out fluid from the lump. If it is a cyst, removing the fluid will cause the cyst to collapse and the lump will disappear. If the cysts reappear, the doctor can simply drain it again.

Biopsy

The only sure way to know if a lump is cancerous is a biopsy. This is where tissue is removed by a surgeon and examined by a pathologist. A pathologist is a doctor who specializes in identifying tissue changes that look like a disease, including cancer. Doctors will biopsy a lump that is distinct and persistent. Tissue samples for biopsy can be obtained either with surgery or with needles. The choice of biopsy depends on the location and nature of the lump. In many cases, the diagnosis will be clear-cut.

TREATING BREAST CANCER

❖ TREATMENTS

Breast cancer treatment for each woman depends on the type of tumor she has, how large it is, how much the cancer has spread, and to where. There are two types of treatment: local and systemic. Local treatments are used to remove, destroy, or control the cancer cells in a specific area. Local treatments include breast surgery and radiation. Systemic treatments include chemotherapy and hormonal therapy.

Local Treatments

Breast Surgery

- Mastectomy is the surgical removal of the breast. There are two types of mastectomy: modified radical mastectomy and simple mastectomy. Modified radical mastectomy removes the breast, the underarm lymph nodes, and the lining over the chest muscles. A simple mastectomy removes only the breast.
- Lumpectomy removes the breast lump. Underarm lymph nodes may be removed to test for possible spread of cancer. Lumpectomy is always followed by radiation.

Radiation Therapy

Radiation therapy is the use of high-energy rays to damage cancer cells and stop them from growing. Surgery is often followed by radiation to destroy any remaining cancer cells. It usually takes 5-6 weeks to complete this therapy.

Systemic Treatments

Chemotherapy is the use of drugs to kill cancer cells. It is called systemic because the drugs enter the bloodstream and travel through the body. A combination of drugs is given by mouth or by injection into a vein or muscle. Chemotherapy is given in cycles: a treatment period followed by a recovery period. It usually lasts 3-6 months.

Hormonal therapy is used to keep cancer cells from getting the hormones they need to grow. This type of treatment can be beneficial to women whose cancer cells have estrogen and progesterone receptors. Hormonal therapy is systemic because it can also affect cancer cells throughout the body.

BREAST CANCER RESOURCES

Leo W. Jenkins Cancer Center

Room 204
P. O. Box 6028
Greenville, NC 27835-6028

(252) 816-7867
1-800-223-9328

American Cancer Society

1021-B Red Banks Road
Greenville, NC 27858

(252) 321-2836

National Cancer Institute Cancer Information Service

1114 First Avenue
New York, NY 10021

1-800-4-CANCER

National Alliance of Breast Cancer Organizations (NABCO)

9 East 37th Street, 10th Floor
New York, NY 10016

1-800-719-9154

National Women's Health Network

514 10th Street, NW, Suite 400
Washington, DC 20005

(202) 347-1140

Y-Me

212 West Van Burin Street
Chicago, IL 60607-3908

1-800-221-2141



School of Medicine

Department of Surgery

919-816-2393 clinic appointments
919-816-2451 after 5:00 p.m.
919-816-2089 fax

MEMO

DATE: March 2, 1999

TO: Speaker's Bureau
East Carolina Breast Cancer Awareness Program

FROM: Frances Swanson, MS
Project Manager

JS

RE: Error in training manual

Please note that we made an error in the training manual on page 10 (Presentation Introductory Statement) in the second paragraph. The correct numbers are:

180,000 women (in the U.S.) will develop breast cancer this year
45,000 women will die from breast cancer each year

These numbers are shown correctly in the brochure entitled "Supporting, Educating, Caring." Please use the correct figures when giving your presentations.

The presentations thus far have been excellent and are being very well received. Please let me know as soon as possible when you have scheduled a program yourself so I can prepare your packet. Also, please let me know if I can help with anything. We now have a TV/VCR and canvas tote bags available for your use when giving the presentations.

Thank you again for your time and participation in this important project.

Biostatistics and Computing
816-2148
M. S. Swanson, PhD

Cardiothoracic Surgery
816-4822
W. R. Chitwood, Jr., MD
J. R. Elbeery, MD
N. A. Francalancia, MD
T. C. Koutlas, MD
R. M. Lust, PhD
J. F. Moran, MD
J. M. Williams, MD

Colon/Rectal Surgery
816-3810
K. G. MacDonald, Jr., MD
W. H. H. Chapman, III, MD
P. G. Meade, MD

Endoscopy 816-4171
K. G. MacDonald, Jr., MD
W. H. H. Chapman, III, MD
M. B. Foil, MD
D. R. Lannin, MD
P. G. Meade, MD

Epidemiology 816-3582
J. M. Dolezal, PhD

General Surgery 816-4751
R. W. Youngblood, MD
W. H. H. Chapman III, MD
P. R. Cunningham, MD
M. B. Foil, MD
D. R. Lannin, MD
K. G. MacDonald, Jr., MD
P. G. Meade, MD
T. N. Patselas, MD
W. J. Pories, MD
L. Tafta, MD

Pediatric Surgery 816-5279
J. C. Fitzpatrick, MD

Plastic Surgery 816-5291
W. A. Wooden, MD
J. C. Benacci, MD
J. F. Lalikos, MD

Surgical Curriculum
816-5262
S. S. Cox, PhD

Surgical Oncology
816-5418
D. R. Lannin, MD
M. B. Foil, MD
L. Tafta, MD

Thoracic Surgery
816-4822/4751
W. R. Chitwood, Jr., MD
J. R. Elbeery, MD
N. A. Francalancia, MD
T. C. Koutlas, MD
J. F. Moran, MD
W. J. Pories, MD
J. M. Williams, MD
R. W. Youngblood, MD

Trace Element Center
816-2963
R. H. Maier, PhD
W. J. Pories, MD

Transplantation 816-2620
C. E. Haisch, MD
P. R. Cunningham, MD
K. M. Verbanac, PhD

Trauma/Critical Care
816-4299
P. R. Cunningham, MD
M. B. Foil, MD
C. E. Haisch, MD
T. N. Patselas, MD

Vascular Surgery 816-4668
C. S. Powell, MD
W. M. Bogey, MD
D. H. Deaton, MD

Greenville,
North Carolina
27604-4004

EAST CAROLINA BREAST CANCER AWARENESS PROGRAM

If you would be interested in a presentation on breast cancer for your group, please complete this form and return to the address at the bottom of the page.

Name: _____

Title or
Business: _____

Address: _____

Phone : (Home) (Work) _____

Please Circle Answers:

Are you a breast cancer survivor? Yes No

Are you interested in having a speaker give a presentation at your church,
business, or organization? Yes No

If Yes:

Group Name: _____

Contact Person: _____

Phone Number: _____

Return to: Frances Swanson, Project Manager
ECU School of Medicine
PCMH, Rm. 304
Greenville, NC 27858
252.816.5418

PRESENTATION SCHEDULE FORM

EAST CAROLINA BREAST CANCER AWARENESS PROGRAM

Date: _____

Name of Contact Person: _____

Phone: (H) _____ (W) _____

Name of Group/Organization: _____

Meeting Location: _____

Directions: _____

Date of Presentation: _____

Time of Meeting/Presentation: _____

Desired Length of Time for Presentation: _____ (minimum of 45 mins. to 1 hr.)

Number of People Expected to Attend: _____

Equipment Available: Yes No Other

VCR

TV

Slide Projector

Screen

Speaker: _____

Phone: _____

Date Speaker was notified: _____

**EAST CAROLINA BREAST CANCER
AWARENESS PROGRAM**

Speaker's Sign Out Form

Please mark the date you pick up and return the following items:

<u>Item</u>	<u>Pick up Date</u>	<u>Return Date</u>
Video	_____	_____
Beads	_____	_____
Breast Model	_____	_____
Evaluation Forms	_____	_____
Other Forms	_____	_____
Bookmarks	_____	_____
Shower Cards	_____	_____
Brochures	_____	_____

Please print your name, address, and phone number below:

Name: _____

Address: _____
(street, po box, etc.)

Phone: _____
(city, state, zipcode)

EC-BCAP PRESENTATION CONTACT FORM

Speaker: _____

Contact: _____

Group: _____

Place: _____

Time: _____ (Start) _____ (Finish)

Participants: # _____

Questions Asked:

Problem Encountered:

Additional Comments:

EC-BCAP EVALUATION FORM

Please fill out this evaluation. This will help us to keep improving our program. We do not need your name because it is confidential.

Group Name: _____

Date: _____

PLEASE CIRCLE YES OR NO

Could you understand the speaker?	YES	NO
Was the speaker Professional?	YES	NO
Did he/she answer any questions?	YES	NO
Did you enjoy the video?	YES	NO
Could you understand the video?	YES	NO
Before now, had you heard other breast cancer stories?	YES	NO
Would you recommend the video to someone?	YES	NO

Please answer all of the following questions:

What did you like the most about the presentation?

What did you like the least?

After watching the video, what are your thoughts on breast cancer?

If you found a lump or knot in your breast, what would you do?

This is a list of scriptures to bring comfort, hope and peace to persons experiencing cancer. Even if you do not have cancer you may have family or friends who are survivors of cancer or presently under treatment.

God calls us to lean upon His strength. God also has equipped doctors with knowledge and skills to battle the disease of cancer. God can use medicine and surgery to heal people with cancer. Share these scriptures with your friends.

All Bible verses are from the King James Version of the Bible unless otherwise noted.

"Come to me all you who are weary and burdened and I will give you rest." NIV, Matt. 11:28

"For this God is our God for ever and ever; He will be our guide even to the end." Psalms 48:14

"Trust in the Lord with all your heart and lean not unto your own understanding; in all your ways acknowledge Him and He shall direct your path." Proverbs 3:5,6

"He gives strength to the weary and increases the power of the weak." NIV, Isaiah 40:29

"I can do everything through Him who gives me strength." Philippians 4:13

"The Lord is my rock, my fortress and my deliverer; my God is my rock in whom I take refuge. He is my shield and the horn of my salvation, my stronghold." Psalms 18:2

"For God so loved the world that He gave His only begotten Son that whosoever believeth in Him should not perish but have everlasting life." John 3:16

"God is our refuge and strength, a very present help in trouble." NRSV, Psalms 46:1

"And the peace of God, which surpasses all understanding will guard your hearts and your minds in Christ Jesus." NSRV, Philippians 4:7

"For I the Lord your God, holds your right hand; it is I who says to you, 'Do not fear, I will help you.'" Isaiah 41:13

"Even when we are too weak to have any faith left, he remains faithful to us and will help us." LB, II Timothy 2:13

"He heals the brokenhearted." Psalms 147:3

"Though I am surrounded by trouble you will bring me safely through them. For your lovingkindness, Lord, continues forever." Psalms 138:7,8

"Though we stumble, we shall not fall headlong; for the Lord holds us by the hand." Psalms 37:24

"Cast your burdens on the Lord, and He will sustain you." Psalms 55:22

"Peace I leave with you; my peace I give you. I do not give to you as the world gives. Do not let your heart be troubled and do not be afraid." NIV, John 14:27

Jesus said, "I have told you these things, so that in Me you may have peace. In this world you will have trouble. But take heart! I have overcome the world." NIV, John 16:33

"The Lord is my strength and my shield; in Him my heart trusts." NSRV, Psalms 28:7

"The Lord is close to the brokenhearted and saves those who are crushed in spirit."
NIV, Psalms 34:18

"I will instruct you and teach you the way you should go; I will counsel you with my eye upon you." NSRV, Psalms 32:8

"For the Lord your God is gracious and compassionate. He will not turn his face from you if you return to Him." NIV, Psalms 30:9

"We do not know what we ought to pray for, but the Spirit Himself intercedes for us."
NIV, Romans 8:26

"For you have been my hope, O Sovereign Lord." Psalms 71:5

"I have loved you with an everlasting love." Jeremiah 31:3

"Then you will call, and the Lord will answer: you will cry for help, and He will say: Here am I."
Isaiah 58:9

"Cast all your anxiety on Him because He cares for you." I Peter 5:7

The East Carolina Breast Cancer Awareness Program

sponsored by
Leo W. Jenkins Cancer Center

Invites You to Attend A Kickoff Reception

**at the Greenville Hilton
Tuesday, October 6, 1998
6:30 P.M.**

Catered Refreshments
**R.S.V.P. by September 30
telephone 816-5418**

Breast cancer

The East Carolina Breast Cancer Awareness Program, sponsored by the Leo W. Jenkins Cancer Center, is hosting a kickoff reception at 6:30 p.m. Oct. 6 at the Greenville Hilton.

Sylvia Dunnavant, author of "Celebrating Life: African-American Women Speak Out About Breast Cancer," will speak.

A new documentary video, "To Live On," which features local women talking about their experiences with breast cancer, will be shown.

The program is a community-wide effort to educate the public on the importance of breast screening and the effectiveness of early detection in treating the disease.

Call 816-5418 by Wednesday.

The East Carolina Breast Cancer Awareness Program is a community-wide effort to educate Pitt County women about the importance of breast cancer screening and the effectiveness of early detection in treating this serious disease. At the reception, we will announce plans for a year-long educational program and premiere our new video, *To Live On*, featuring local women talking about their experiences with breast cancer. Sylvia Dunnavant, inspirational author of *Celebrating Life: African-American Women Speak Out About Breast Cancer*, will speak at the event. Please join us for this exciting evening and help support our efforts to fight breast cancer in Pitt County.

You are invited

to attend the
**East Carolina
Breast Cancer Awareness Program
Kickoff Reception**
Greenville Hilton Inn
Tuesday, October 6, 1998

6:30 pm

Refreshments
RSVP by September 30 252.816.5418

www.uhseast.com

LEO W. JENKINS CANCER CENTER
University Health Systems of Eastern Carolina

East Carolina Breast Cancer Awareness Program Community Advisory Board

Linda Bond	E. C. Land
Marian Carson	Sidney Locks
Connie Clark	Julius Mallette
Jennifer Congleton	Linda Mayne
Randy Curtis	Lois Reddrick
Julia Davis	Randy Royal
Phyllis DeAntonio	Ceylon Rowland
Donald Ensley	Terry Shank
Minerva Freeman	Anna Shappley
Linner W. Griffin	Edward Treadwell
Donna Harris	Carmen Vincent
Ernestine Haselrig	Scott Wells
Phyllis Horns	David White
Rhonda Jordan	Marian Gorham Wilkes
Dorothy Josey	

Breast cancer speakers bureau started

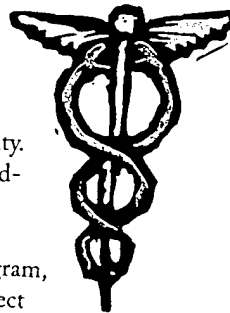
The East Carolina Breast Cancer Awareness Program, a community education program affiliated with the Leo W.

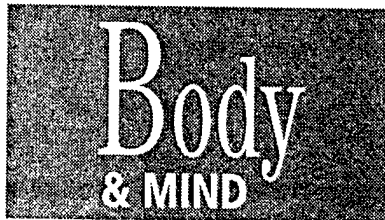
Jenkins Cancer Center and the East Carolina University School of Medicine, is offering a speakers bureau to present programs to local church and civic groups in Pitt County.

The presentation consists of a 30-minute video, "To Live On," which features six eastern North Carolina women discussing their experiences with breast cancer and local doctors discussing facts and treatment options. The trained speaker will present a brief introduction to the video, then lead a discussion and answer questions from the audience about breast cancer.

This presentation is a free public service to the community.

If you are interested in scheduling the program or learning more about the East Carolina Breast Cancer Awareness Program, contact Frances Swanson, project manager, at x5418.





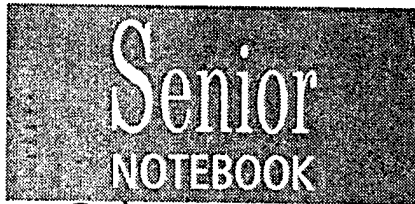
is operated by the Greenville Recreation and Parks Department.

Call 329-4041.

Breast cancer

The East Carolina Breast Cancer Awareness Program is offering free educational presentations to Pitt County church and civic groups. Presentations will include a 30-minute video, "To Live On," where six local women discuss their experiences with breast cancer and physicians talk about treatment options and current facts on the disease.

To schedule a presentation, call Frances Swanson at 816-5418.



D. Reflector 4-17-99

Winterville club

The Winterville Senior Citizens Club is scheduled to meet from 10:30 a.m. to 2 p.m. Tuesday at the Winterville Community Center.

A program about breast cancer awareness will be presented by a representative of the East Carolina University School of Medicine.

Early detection and family support after diagnosis will be emphasized.

Also, a fall trip to Washington, D.C., including shopping at the Potomac Mills Outlet, is being planned by the group for Sept. 11. Call 355-2572.

today's health

A LISTING OF SEMINARS, SUPPORT GROUPS, SCREENINGS,
SPECIAL PROGRAMS AND COMMUNITY EVENTS OFFERED BY
UNIVERSITY HEALTH SYSTEMS OF EASTERN CAROLINA

www.uhseast.com

Cancer

Support groups offered in conjunction with the American Cancer Society.

Call the Leo W. Jenkins Cancer Center at 816-7867 for more information.

Hope Again, a monthly bereavement support group. Meets every third Thursday, noon, University Home Care Conference Room, #6 Doctor's Park, Greenville. Next meeting is May 20. Call Ellen Walston at 816-7943 for more information.

Fatigue Management, educational program to help you manage cancer-related fatigue. Offered on May 18, 12:30-1:30 pm. Call 816-7943 to register.

East Carolina Breast Cancer Awareness Program, educational video presentation available to community, church and business groups upon request. Contact Frances Swanson at 816-5418.

Made in the Shade, a support group for patients with melanoma. Meets the last Thursday of every month, 6:30-8:00 pm, second floor of the Leo W. Jenkins Cancer Center.

Living On After Loss, a support group for people dealing with the loss of a family member or loved one. The 8-week series consists of two educational sessions and six support sessions. Group meets at Spring Arbor Assisted Living Center, 2097 W. Arlington Boulevard, Greenville. Call 816-7943 to register.

***WHAT HAVE YOU
HEARD ABOUT BREAST
CANCER?***

LEARN THE FACTS AND FIGURES

**FARMVILLE PRESBYTERIAN CHURCH
310 GRIMMERSBURG STREET
FARMVILLE, NC**

**SUNDAY, MAY 2, 1999
4:00PM**

Refreshments will be served.

The best protection is early detection.

**East Carolina Breast Cancer Awareness Program
816-5418**

Getting the word out

Breast cancer program takes message to county residents

By Jeannine Manning Hutson, staff writer

The women of the Sappho Book Club have been meeting for almost 20 years, talking about recent good reads, sharing news of children and grandchildren.

During a recent meeting at Parker's Barbecue in Greenville, they had a special guest speaker: Dr. Kathy Kolasa, a nutritionist and professor of family medicine at the East Carolina University School of Medicine.

Her topic wasn't the new Martha Stewart hors d'oeuvres cookbook or Jan Karon's latest Mitford novel. Instead, it was something more important: breast cancer.

Kolasa is one of 23 ECU breast care experts and volunteers who go out to groups like the book club to lead a discussion about breast cancer through the East Carolina Breast Cancer Awareness Program. After the attendees watch "To Live On," a video focusing on breast cancer in eastern North Carolina, the ECBCAP volunteer leads a discussion about breast cancer and answers questions people may have.

The group works to educate Pitt County women about breast cancer and negate myths regarding the disease. In the 27-minute video, women talk about their fears of breast cancer and how they overcame them in the process of seeking treatment.

The Sappho Book Club is testament to the frequency of the disease—one member is recuperating from a mastectomy, and two or three other members have had advanced testing after a routine mammogram showed something suspicious, according to club president Carrie Oakley of Greenville. "I'm sure the video helped them talk about it that day. They probably would have shared that news with the group anyway, but (the video) was an asset," she said.

Education is key

"The video serves as a vehicle to get people talking about breast cancer," Kolasa said. That is one of the most important aspects of cancer education—dispelling the wives' tales about seeking treatment, like the idea that air getting to the cancer during surgery can make it spread.

Program leaders hope that through educational efforts women, especially African Americans, will be better able to make educated choices when breast lumps are detected. Socioeconomic factors combined with cultural beliefs and attitudes play a role in the delayed diagnosis of breast cancer in African-American women, according to an eight-year study led by Dr. Donald Lannin, an oncology surgeon at the ECU School of Medicine. The study was published last year in the *Journal of the American Medical Association*.

"We think some of the myths prevent people from coming in with early symptoms of breast problems," said Lannin, who is also director of the Leo W. Jenkins Cancer Center. "Like all cancers, the earlier you can catch breast cancer, the better the treatment options are for the patient."

Health care providers like Lannin, along with a group of volunteers, give the presentations in the community.

The ECBCAP held training for members of its

speakers bureau in January and began in February with the presentations to Pitt County groups. So far, the ECBCAP has presented the video to more than 35 groups.

A grant from the Department of Defense is funding the project through September 2000. The three-year project breaks down like this: 1998 was the research year for pre-intervention data; 1999 is the intervention year with a strong push for education through the presentations; 2000 will be the post-intervention year with data collected to see how the speakers bureau presentations have impacted the community and if they have prompted women to seek medical treatment for a breast lump sooner rather than later.

One of the volunteers in the speakers bureau has experience as a nurse working with cancer patients and as a breast cancer survivor.

"A very needed message"

Sylvene Spickerman, a retired ECU School of Nursing faculty member, leads several ECBCAP presentations each month. She's presented to church groups, the Greenville Community Shelter, retirement facilities and even a local card shop.

The shop owner paid his employees for the hour they came in early one Saturday for Spickerman's presentation. "They were a young group but very interested. And he (the shop owner) was as involved in the video as they were," she said.

Spickerman, who is also an active American Cancer Society volunteer, said she is interested in doing anything that will help push women to have annual mammograms after the age of 40, perform monthly breast self exams and have an annual physical.

"I see 'To Live On' sending out a very needed message," she said. "The video shows how patients who are found to have late-stage cancer make prognosis poor and treatment difficult."

She also volunteers with the American Cancer Society's Reach for Recovery program, which pairs a breast cancer survivor with a newly diagnosed breast cancer patient.

"I've sent many patients to the operating room, but nothing prepares you for when it's you (as the cancer patient)," she said.

Volunteers like Spickerman are helping make the grass-roots ECBCAP work, according to program manager Frances Swanson of the ECU Department of Surgery.

"The volunteers who have survived breast cancer often tell their audience about how they found their own lump," Swanson said. "I have heard from people attending how they appreciate that the volunteer told her own story."

Even though it's effective for medical providers, like a physician, to give the presentations, Swanson said the volunteers are living examples of why early detec-

tion is so important.

"When you have someone standing up there saying, 'Look, I had breast cancer.' It makes a great impact," Swanson said.

She added that the volunteers don't give medical advice to those attending. "We don't hesitate to say, 'I don't know. You need to ask your physician about



Sylvene Spickerman, breast cancer survivor, retired nurse and ECBCAP volunteer, talks to a group of eastern North Carolina women about breast cancer. Photo by Linda Fox

that," she said.

Swanson has several stories of how the video and speaker got people talking about breast cancer or seeing their physician.

One example: On a cold, damp night in February with the threat of snow looming, a group of women met in Pactolus. Members of all churches in the community—black and white—had been invited to attend the presentation.

Only one black woman came. She told the group she didn't know why she was there, but she had been drawn to come that night even with the threat of bad weather.

Later that week, the woman's 28-year-old daughter-in-law, only days after giving birth to her second child, was diagnosed with breast cancer.

"I couldn't believe it," Swanson said. "There are several stories like this where the disease is affecting the person attending or her family and they just don't know it yet."

After the presentation by the volunteer speaker, the attendees complete evaluation forms. One of the questions asks, "If you find a lump or knot in your breast, what would you do?" The majority respond that they would see their physician right away.

"That's what we hope they'll say and more importantly what we hope they would do," Swanson said.

"This video gets everyone's attention. We just need to get out there more and more," she said. "This disease doesn't distinguish between social classes or races, and we still have a lot of educating to do," she said.

"The volunteers who have survived breast cancer often tell their audience about how they found their own lump. I have heard from people attending how they appreciate that the volunteer told her own story."

—Frances Swanson, program manager

Day Break Cable Channel 7
New East Communications
Mike Sullivan, Host

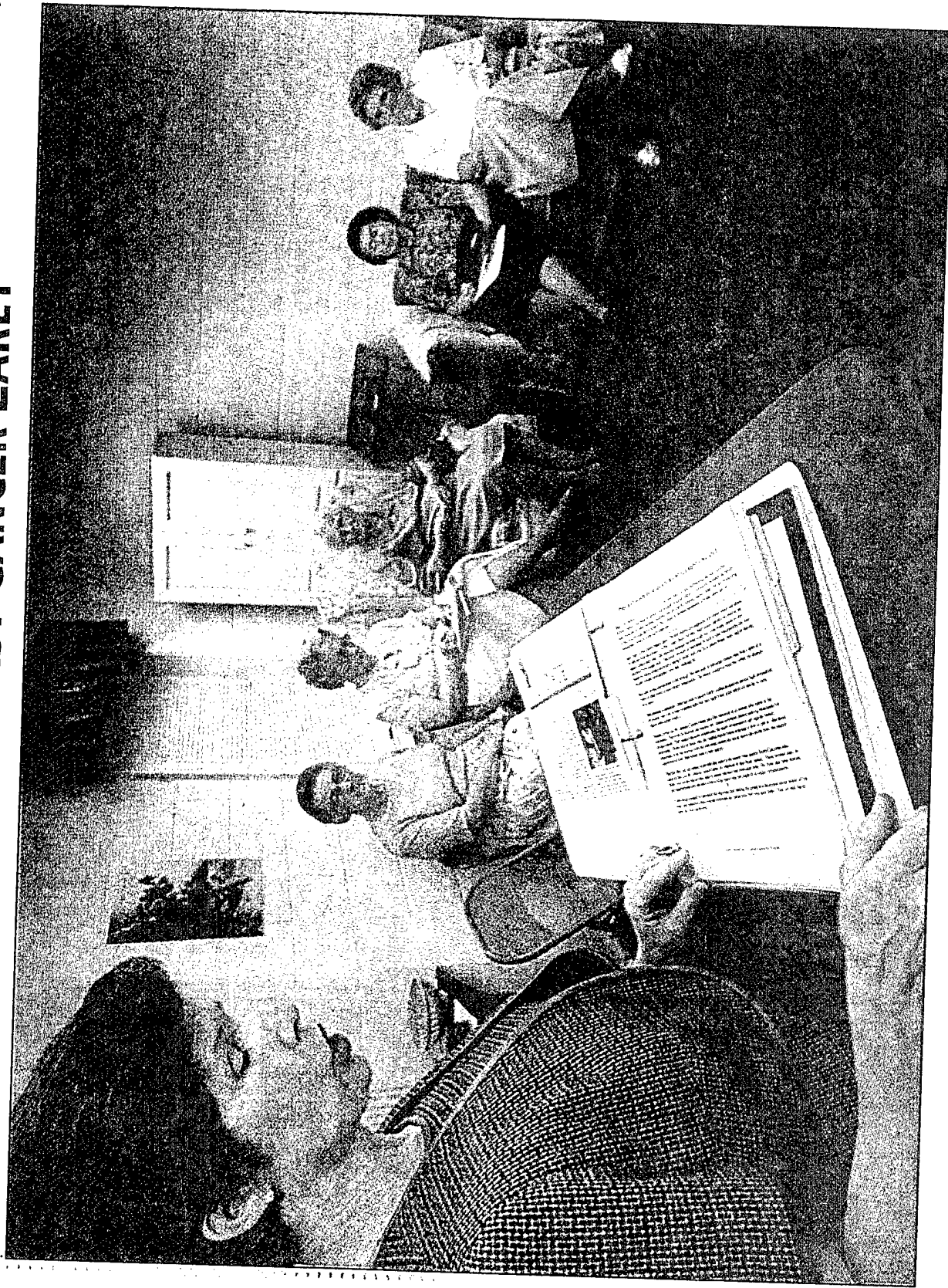
East Carolina Breast Cancer Awareness Program
6/22/99 7:40 am

Guests:

Frances H. Swanson, MS, Project Manager
Benita Williams, Research Assistant, Medical Student

1. What is the East Carolina Breast Cancer Awareness Program?
2. Who presents the programs and where are the programs held?
3. What is the video about?
4. Are you contacting physicians?
5. What is the goal of the Ob-Gyn intervention?
6. How is the Generation to Generation program implemented in the Ob-Gyn practices?
7. What can our viewers do to help in the fight against breast cancer?
8. What procedures or examinations do women need to do in order to detect breast cancer early?

FIGHTING BREAST CANCER EARLY



DONNA HARRIS, left, gives a breast cancer presentation Monday to Unity Free Will Baptist Church members Ellen Anderson, far left, Christine Langley, Lillian Buck, Janie Radford and Louise Reel. Harris, a breast cancer survivor, is a volunteer with the East Carolina Breast Cancer Awareness Program.

Greg Eans/The Daily Reflector

Breast cancer survivors educate public about disease

By Jenna Hunt
The Daily Reflector

Donna Harris has found a new calling since she discovered a lump and doctors successfully treated her for breast cancer.

Since February, she's visited churches, book clubs and civic groups encouraging women to perform self breast exams, have regular mammograms and seek early treatment if a lump is detected.

She is one of 23 volunteers with the East Carolina Breast Cancer Awareness Program, spreading the

word about the disease to women throughout Pitt County.

"It's so important to share the message," she said. "There are women who find (a lump) and ignore it thinking it will go away. No matter how insignificant you think it is, go to the doctor."

The three-year program is a joint effort of community members and faculty and physicians at East Carolina University School of Medicine and the Leo W. Jenkins Cancer Center. Seven months into the

See *CANCER*, B3

Are you at risk for breast cancer?

Breast cancer is the most frequently occurring cancer in women. About one in eight women will get the disease sometime in her life. The following factors increase the likelihood for developing breast cancer:

- Age older than 30
- A family history of breast cancer (Still, about 80 percent of the women who develop the disease have no history of it in their family)
- Starting menstruation before age 12
- Having first child after age 30
- Never having a child
- Beginning menopause after age 55
- Long-term use of estrogen replacement therapy or birth control pills
- Alcohol use

The Daily Reflector, Tuesday August 10, 1999

CANCER

Early detection key to survival, doctors say

Continued from B1

public education portion of the project, Harris and the other volunteers have delivered their message to women in more than 35 organizations. About half of the volunteers are breast cancer survivors, said Frances Swanson, East Carolina Breast Cancer Awareness Project manager.

"I think they are very effective in spreading the message because they don't just talk the talk, they walk the walk," Swanson said. "They are very open about their own experiences with breast cancer."

On Monday Harris visited with senior citizens at Unity Free Will Baptist Church in Greenville.

Each year in the United States, about 180,000 women are diagnosed with breast cancer and about 45,000 die, Harris told the group.

Her presentation included a breast exam demonstration, discussion and a 27-minute video called "To Live On." The video shows six women from eastern North Carolina talking about their struggles after discovering breast cancer and the process of seeking treatment. One 31-year-old woman in the video is from Greenville.

Breast cancer is curable when found in the early stages. When ignored or undetected, the disease worsens and can spread into the lymph nodes, liver, bones and brain, Swanson said.

"Early detection is the single most important thing," said Dr. Donald Lannin, an oncology

surgeon at the ECU School of Medicine.

In the early stages women have a survival rate of about 90 percent. In the final stages the rate drops to 25 percent or less, said Lannin, also director of Jenkins Cancer Center.

The key to finding breast cancer early is routine screening with yearly mammograms — an X-ray of the breast. Mammograms can detect breast cancer up to two years before it can be seen or felt. It can detect tumors about the size of a ball-point pen tip.

The American Cancer Society recommends yearly screenings for all women older than 40. Women older than 20 should have regular breast exams by a doctor and perform monthly self-breast exams, Harris said.

Harris, 50, discovered the hard lump on the inside of her right breast early in January 1992 as she was drying off after her morning shower.

"It was a hard little knot about the size of a robin egg. (It) did not hurt," she said. Immediately, she knew she had to see her doctor and made an appointment.

Yet, she kept telling herself it couldn't be cancer because she was only 43, didn't have a history of breast cancer in her family and no other risk factors.

"I was a very healthy woman," she said. She exercised regularly, was slim, ate a nutritious diet and had two mammograms before she was 40, "just to be sure."

Her doctor performed a needle biopsy of the lump, but couldn't get an accurate reading. The results of a mammogram were sent to Chapel Hill and still the diagnosis could not be determined.

An ultrasound was recommended and Harris scheduled an appointment.

"I had become very aggressive

about it," Harris recalled.

After her ultrasound the doctor told her it needed to come out, she said. She had surgery the same day.

"I wanted it out," Harris exclaimed. "I thought it would just be a cyst, but I had a little nagging feeling in the brain it could be cancer."

Her fears were confirmed — she had a fast growing form of breast cancer. However, it had not spread to other areas of her body.

She caught it in time, but it could still spread, doctors told her.

Her husband of 30 years was by her side during the procedure and was the first to hear from the doctor.

Harris had two options, take only part of her breast where the tumor had formed or have a complete breast removal.

"My husband asked the doctor — 'If this was your wife what would you recommend?'"

The doctor said he'd recommend a removal or mastectomy of her right breast.

Harris knew the risks and said "take the breast." She said she didn't want any chance of the cancer lingering in her body.

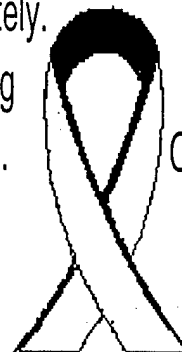
After the mastectomy surgery and eight treatments of chemotherapy Harris has completely recovered. She returns to her doctor every six months and has yearly mammograms.

"I'm thankful and feel very fortunate," Harris said. "That's one of the reasons I've become involved in the program. I feel it is my purpose in life to get the message out to other women."

To schedule a free presentation on breast cancer call 816-5418. For more information about breast cancer contact the Jenkins Cancer Center 816-7867 or American Cancer Society 321-2836.

***Don't be scared
Be informed about breast cancer***

Breast cancer is 90% treatable when found early and dealt with immediately. You can make a difference by getting regular breast exams and mammograms. Consult your doctor at once if you find a lump or knot in your breast.



Early detection is the best protection

This message is brought to you by The East Carolina Breast Cancer Awareness Program in cooperation with the ECU School of Medicine and The Leo W. Jenkins Cancer Center. Tel 252-816-5418

***Don't be scared
Be informed about breast cancer***

Some women think that breast cancer may lead to the loss of intimacy and support from their husbands or boyfriends. However, this is not always the case. The couple needs to express their concerns and fears to each other. Together they can fight breast cancer.



Early detection is the best protection.

*This message is brought to you by The East Carolina Breast Cancer Awareness Program in conjunction with the ECU School of Medicine and The Leo W. Jenkins Cancer Center.
Tel: 252-816-5418*

***Don't be scared
Be informed about breast cancer***

You may have heard people say that removing a tumor or exposing it to air causes cancer to spread. This is not true. Cancer will spread if not removed. Surgery is often the first and most effective treatment for cancer.



Early detection is the best protection.

*This message is brought to you by The East Carolina Breast Cancer Awareness Program in conjunction with the ECU School of Medicine and The Leo W. Jenkins Cancer Center.
Tel: 252-816-5418*



School of Medicine

Breast Clinic

East Carolina University

Greenville, NC 27858-4354

252-816-3570 office • 252-752-4163 after 5pm

Donald R. Lannin, MD

Walter J. Pories, MD May 20, 1999

David W. Pearsall, MD

OB/GYN
ADDRESS
ADDRESS
ADDRESS

Dear Dr.

The East Carolina Breast Cancer Awareness Program (ECBCAP), funded by a grant from the Department of Defense, is underway in Pitt County. As part of this project, we are presenting educational programs and distributing educational materials on breast cancer throughout the county. Our previous research has conclusively demonstrated that OB/GYN physicians are the most active speciality in breast cancer screening and early detection. The problem we have identified is that post menopausal women, who are at highest risk for breast cancer, frequently are least likely to see an OB/GYN physician and get the screening and education that they require. To overcome this problem we have developed a strategy which we would like to test in Pitt County where patients who see their OB/GYN physician are asked to bring educational materials to their older female relatives.

Would you be willing to let your practice participate in this pilot project? We have a medical student and a health education graduate student who are working in our office over the summer to assist on this project. If you agree, they could visit your practice and help work out customized details which would fit best with your individual practice. It would be helpful if you could identify a person for them to contact. This really should not interfere with any of your normal routines and would most likely be seen as a very beneficial service by your patients.

By the way, we have produced a wonderful new video, "*To Live On*", which follows six breast cancer patients undergoing diagnosis and treatment for breast cancer. We use this routinely in breast cancer education events and it has been very well received. If you would be interested in having one of our volunteers show this video to either your patients or office staff we would be delighted to arrange this.

I will try to talk with you or one of your partners in the next week or two and see if you would be willing to participate. If you have any questions about this, please call either myself or Frances Swanson, our project manager, at (252) 816-5418. Thank you in advance for your support of this important endeavour.

Sincerely,

Donald R. Lannin, M. D.
Professor of Surgery

DL/agb

Generation To Generation

Try the following true or false quiz and see how much you know about families and breast cancer. The correct answers are found on the back.

- | | | |
|---|----------|----------|
| 1. Breast cancer is the most common cancer found in women. | T | F |
| 2. Over 75% of all breast cancers are found in women over age 50. | T | F |
| 3. African-American women are more likely to die from breast cancer than are white women. | T | F |
| 4. A women is at higher risk for breast cancer if her mother, sister, or daughter have had the disease. | T | F |
| 5. Breast cancer is very curable if it is found early. | T | F |
| 6. Women ages 50 and older should have a mammogram every year to check for and prevent breast problems. | T | F |
| 7. Women over age 50 are less likely to get regular medical care than are younger women. | T | F |
| 8. A woman is much more likely to get a mammogram if her own close family members encourage her. | T | F |
| 9. Medicare and Medicaid will pay for one mammogram a year for women over age 40. | T | F |

Generation to Generation Project Information Sheet

As you learned from the quiz, older women have a greater chance of developing breast cancer yet they are often less likely to get regular medical care, specifically annual breast exams and mammograms. *You can make a difference.* Older women are more likely to have breast exams or mammograms if someone in their family encourages them to do so.

Show someone you care. Please think about taking some information on breast cancer to your older female relatives in Pitt County. To obtain this material, answer the following questions for us:

1. Do you have any female relatives ages 50 or over living in Pitt County?
_____ Yes _____ No

2. **If yes**, would you be willing to take or send them a greeting card with information inside about breast cancer?

_____ Yes _____ No

If yes, please answer the following questions for us and turn this sheet back in to the office staff.

3. Which of these female relatives, age 50 or over, do you have who live in Pitt County?

- () Mother
- () Grandmother(s) How many? _____
- () Sister (s) How many? _____
- () Aunt(s) How many? _____
- () Daughter(s) How many? _____
- () Cousin(s) How many? _____
- () Great grandmother(s) How many? _____
- () Others? Which relatives and how many? _____

4. Please give us:

Your name: _____

Your birthdate: _____ Your ethnicity/race: _____

Your address: _____

Your Phone No. _____

**** Please return this sheet to the office staff. ****

Appendix B

EAST CAROLINA
BREAST CANCER AWARENESS PROGRAM
SPEAKER'S BUREAU

Linda Bond 106 Willow Dr. Williamston, NC 27892	(H) 792-7364 (W) 816-4395	Health care worker Not available M, W, F nights until after May
Dianne Bowen PO Box 2151 Greenville, NC 27836	(H) 757-3632	Breast cancer survivor Day hours best
Joyce Bryant 3011 Phillips Rd. Greenville, NC 27834	(H) 355-6174 (W) 816-2900	Health care worker Partners educator Not available days
Jennifer Congleton 2718 Royal Dr. Winterville, NC 28590	(H) 756-1033 (W) 816-5575	Public health educator Not available W and F nights
Lena Darden 400 Wilson Dr. Ayden, NC 28513	(H) 746-8264	Nurse & Partners Not available 1 st & 3 rd Tuesday nights
Karen Elbersson 505 Potomac Dr. Chocowinity, NC 27817	(H) 975-1536 (W) 328-2332	Nurse/Health care educator/provider Availability varies
Samantha Graves 1286 Park West Dr., Apt. 3 Greenville, NC 27834	(H) 752-6654	Medical student Not available M-F until after 3
Donna Harris 501 Oakdale Dr. Ayden, NC 28513	(H) 746-2297 (W) 746-2161	Breast cancer survivor Not available 1 st Th, 3 rd T, and M or F nights
Ernestine Haselrig 1100 Fairfax Ave. Greenville, NC 27834	(H) 758-4545 (W) 413-1421	Nurse Not available Th and F nights; days vary
Donna Hollar PO Box 3691 Greenville, NC 27836	(H) 551-3722 (W) 328-6968	Breast cancer survivor Not available 8-5 days
Kathryn Kolasa 3080 Dartmouth Dr. Greenville, NC 27858	(H) 756-5487 (W) 816-5459	Nutritionist
Katheryn Lewis 3298 Yankee Hall Rd. Greenville, NC 27834	(H) 752-6936 247-5917	Daughter is breast cancer survivor. Generally available.

Cindy Maynard
204 Hillcrest Dr.
Farmville, NC 27828

(H) 753-4774
(W) 816-2900

Nurse
Days can be arranged,
works M-F 8-5

Bernice McElrath
PO Box 962
Robersonville, NC 27871

(H) 795-4175

Breast cancer survivor
Not available nights

Theresa Faye Mitchell
1701 S. Main St., Apt. J
Farmville, NC 27828

(H) 753-5319

Breast cancer survivor
Not available mornings

Juanita Nobles
605 Lyndale Dr.
Ayden, NC 28513

(H) 746-4899

Partners educator
Time is limited

Joyce Owens
206 Westhaven Rd.
Greenville, NC 27834

(H) 355-3431
(W) 816-4145

Breast cancer survivor
Health care worker
Availability varies

Patricia Smith
107 Allen St.
Farmville, NC 27828

(H) 753-3419
(W) 816-2500

Breast cancer survivor
Not available M-F
noon-2 PM usually

Sylvene Spickerman
103 Regalwood Rd.
Greenville, NC 27858

(H) 355-4872

Breast cancer survivor
RN; generally available

Melba Rhue Tripp
104 Marion Dr.
Greenville, NC 27858

(H) 756-4422
(W) 328-1932

Breast cancer survivor
Not available early AM

Carmen Vincent
3256 Landmark St., Apt A3
Greenville, NC 27834

(H) 355-7712
(W) 816-4734

Health care worker
Not available M & Th
until after March

Eleanor Vines
2705 Jackson Dr.
Greenville, NC 27858

(H) 758-9097
(W) 816-3570/2393

Health care worker
Not available 8-5 M-F
and Wed. nights

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Medical student
Not available 8-3 M-F

EAST CAROLINA BREAST CANCER AWARENESS PROGRAM

<u>Month</u>	<u># of programs</u>	<u># of people attending</u>
October, 1998	3	48
November, 1998	4	52
December, 1998	--	--
January, 1999	--	--
February, 1999	3	91
March, 1999	5	73
April, 1999	9	107
May, 1999	12	200
June, 1999	9	105
July, 1999	2	23
August, 1999	2	30
September, 1999	7 scheduled	55
	<hr/>	<hr/>
TOTALS	56	784

These figures are as of September 9, 1999.

This does not include the kick-off held October 6, 1998 at the Greenville Hilton Inn that was attended by about 250 community leaders.

PROBLEMS ENCOUNTERED WITH PRESENTATIONS

Problem	Effect/Reason	Frequency
Cancelled program	Only 30 minutes available for meeting	1
Inclement weather	Decreased attendance	2
Group did not meet	Speaker was at site on correct date and time scheduled, but group was not present	2
Site managers at senior citizen centers were not aware presentation was scheduled	County coordinator vacated position; program still presented	2
Time available for programs	Time limits at work site or club did not allow sufficient time for discussion or question/answer session	3
Hurricane Floyd	Programs cancelled due to massive flooding and power outages	4

SUMMARY OF COMMENTS ON PRESENTATION EVALUATION FORMS

What did you like most about the presentation?

Questions and answers

The video

Information, especially from a breast cancer survivor

Sincerity of the speakers

Patients in the video

The personal approach

The use of the breast model to learn how to detect lumps

The shower card reminder to do breast self exam

The real people and real stories

Explanation of how to examine my breasts

The attitude of the people in the video

The pamphlets

Information on mammograms and guidelines

"Everything"

Input from breast cancer patients

Information relevant to eastern North Carolina

The very knowledgeable speaker

The man who accepted his wife's condition

Education

Support from husband, family, and friends depicted in the video

Encouragement from breast cancer patients

The presenter dispelling myths about breast cancer

Courage of patients in the video

The necklace of beads showing sizes of breast lumps detected by various methods

What did you like the least?

The lengthy video

Sadness of the video

Nothing

Not having enough time

The statistics

Reality

Idea that the young mother in the video might die

Fear

The heartache

Video was too short

Church groups in the video

After watching the video, what are your thoughts on breast cancer?

Scary
Need to examine my breasts regularly
Schedule an appointment for a clinical breast exam
Not as scared now
Get a mammogram
Breast cancer is treatable with early detection
Concerned
Appreciate every moment of my life
I'm more aware now
Be responsible for your own health
You can be cured
Breast cancer could happen to anyone
Get the word out about the importance of mammograms and breast exams
"Never let fear stop you"
Breast cancer is more prevalent than I thought
It is nothing to be ashamed of
Tell everyone to check her breasts
I will get a mammogram
You don't have to die from it
More positive about a cure
Admiration for the patients

If you found a lump or knot in your breast, what would you do?

See a doctor immediately
Don't delay
Pray
Discuss with my husband then call the doctor
"Call on God and then call the doctor"
Call the doctor and then cry
Cry, then call a doctor
Demand a biopsy
"Run to the doctor"

QUOTATIONS FROM EVALUATION FORMS

"I am a physician and this was very well done!" (Kiwanis Club)

"I'm 95 years old so I wouldn't do anything if I found a lump in my breast." (Cypress Glen Retirement Center)

"I would seek help immediately or maybe even head out to the emergency room. I don't think it's smart to take your body for granted in any way." (New Directions Shelter for Women)

"With God, all things are possible. The doctor can diagnose and treat, God heals." (Tender Care Nursing Services)

"It can get you down, but just look to the Lord for help through the doctor." (Retired Federal Employees)

"Go immediately to the doctor because I have had my mother and a sister to die of breast cancer." (St. James United Methodist Women)

"It's very curable, can be overcome, and doesn't have to change your life for the worse." (St. James UMW)

"The best part was women sharing their hopes, faith, fears with one another and telling us that treatment can be a lifesaver." (JC Penney employee)

"Everything was great—the speaker, video. I don't have a least." (JC Penney employee)

"There is life after a mastectomy." (A 20 year breast cancer survivor, Kiwanis Golden K Jewels)

"Everyone should be more aware, take care of yourself and all the females in your life." (Nursing assistant)

"It's not a death sentence. You still can live a normal life after breast cancer." (Tender Care Nursing)

"I'm calling tomorrow for a mammogram." (Farmville United Methodist Women)

"Breast cancer, although frightening, isn't a death sentence." (Farmville Presbyterian Women)

"I'm ready to go home and do my exam." (First Christian Church)



School of Medicine

**MEDICAL
STUDENT
RESEARCH
DAY**

Brody Auditorium • August 16, 1999 • 1:30 pm-6:00 pm

Generation to Generation: An Intervention Enlisting Younger Women to Teach Older Family Members about Breast Cancer

Benita Williams, Donald R. Lannin, MD; Holly F. Mathews, PhD; Jim Mitchell, PhD; Melvin S. Swanson, PhD; Frances H. Swanson, MS; Shantelle Carter, Maxine S. Edwards, RN

Breast cancer is the most prevalent cancer among women. Although more white women are diagnosed with breast cancer, more black women succumb to this disease. The most important reason for this difference in mortality is that black women present with more advanced stage breast tumors. It has been found that a lack of screening and cultural beliefs each contribute to black women presenting with advanced stage breast cancer. Based on these findings, a community-wide intervention was implemented to increase awareness to lead to early detection of breast cancer throughout Pitt County.

Generation to Generation is an intervention conducted through Ob-Gyn practices in which young women will encourage their older relatives to get mammograms and do monthly self-breast examinations. The rationale for this is that previous research has shown that whereas white women most frequently turn to their husband or boyfriend for medical advice, black women most frequently rely on female relatives for such advice. Materials developed include a quiz addressing myths and facts about breast cancer, pamphlets, a greeting card provided by Hallmark, a pre-paid response postcard, and posters to display at the sites. The effectiveness of the intervention will be evaluated by 1200 interviews, 600 in Wilson County (control) and 600 in Pitt County (experimental). Other measures include post cards returned by older relatives, follow-up with Generation to Generation participants, and Ob-Gyn practice feedback. It is hoped that this program becomes a model for breast cancer awareness nationwide.

Generation to Generation

**An Intervention Enlisting Younger Women to
Teach Older Family Members about
Breast Cancer**

Breast Cancer Cases

Race

• **White** 532 (71%)

• **Black** 212 (29%)

• **Japanese** 1

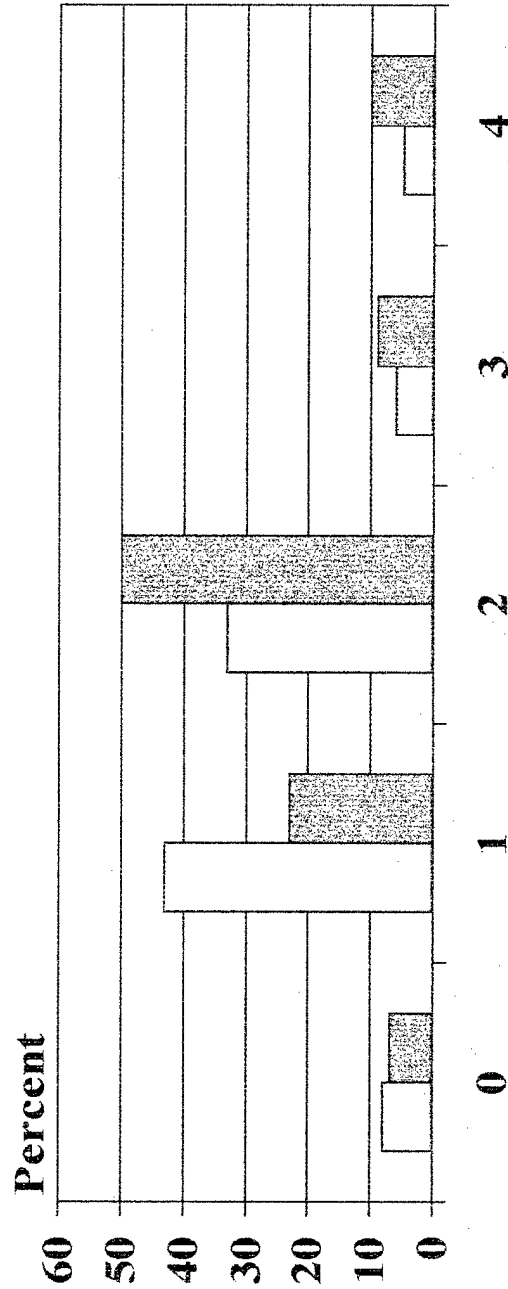
• **Korean** 1

• **Other** 1

Breast Cancer Stage

PCMH Registry 1988-1993

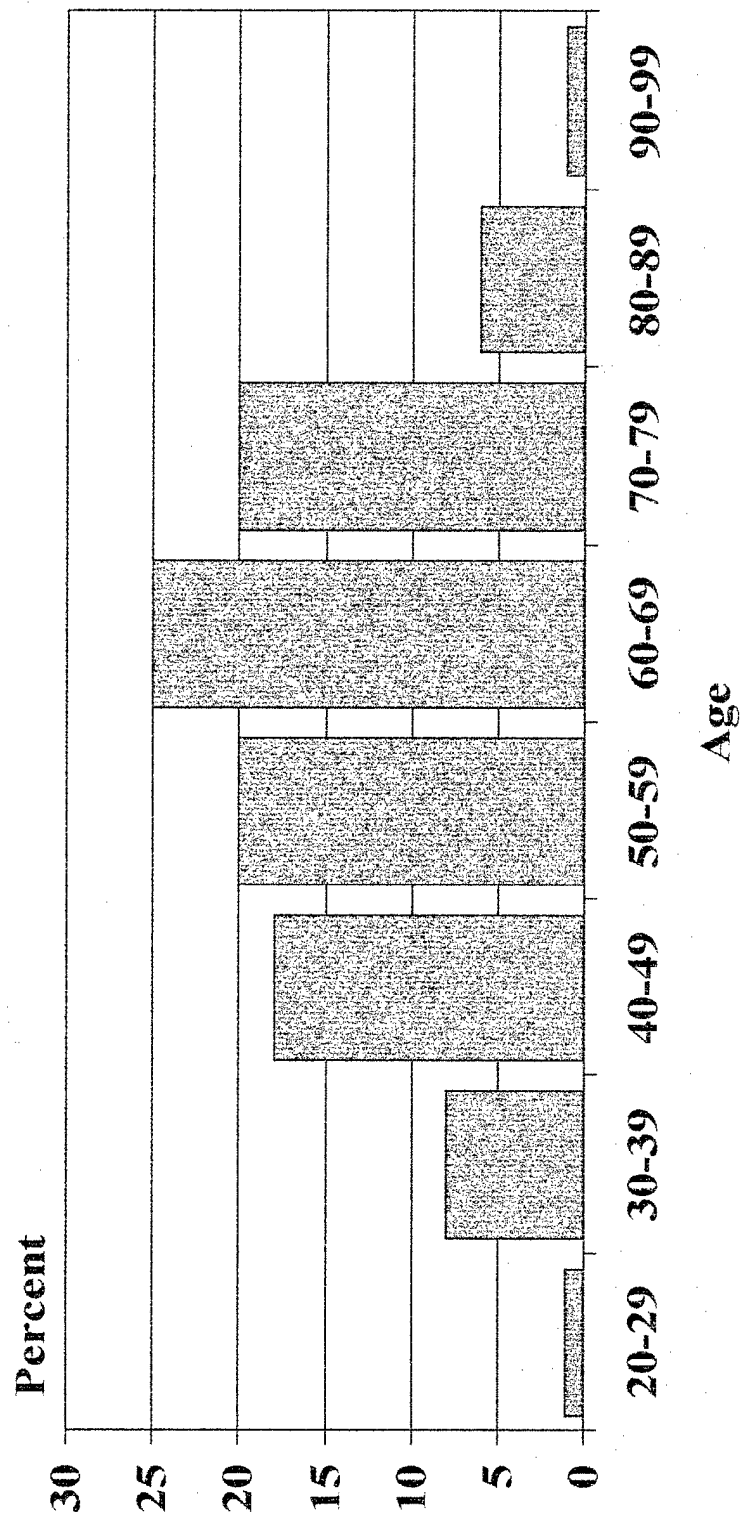
□ White
■ Black



$p < .00001$

Breast Cancer Cases

Age at Diagnosis



Who are the Confidants?

	White	Black
--	-------	-------

Husband/boyfriend	37%	18%
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Mother/sister/daughter	29%	45%
------------------------	-----	-----

Other	34%	37%
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$p < .0005$

Patient Married?

	White	Black	n
Ever married	96%	87%	
<.0001			
Currently	63%	41%	<.001
married			

Who are the Confidants?

If currently married

White

Black

Husband/boyfriend

57%

38%

Mother/sister/daughter

20%

37%

Other

23%

25%

p < .01

Rationale for Intervention

- 1. Ob-Gyn doctors are most interested in breast screening.**
- 2. However, most patients are young and older women do not see Ob-Gyn doctors.**
- 3. The risk of breast cancer increases with age.**
- 4. Black women tend to rely on female family**

Generation 10 Generation

- **July - October**
- **4 practice sites (including Health Dept.)**
- **Materials include:**
 - **Instructions**
 - **Quiz, True/False with Answers**
 - **Packet of information to give to relative**

Process

1. Patient receives instructions and quiz from office staff to complete while waiting.

PROCESS

2. Patient returns yellow sheet to office staff, indicating how many relatives she has in PITT COUNTY.

PROCESS

3. Patient is given packet to give to Older relative.

Packet includes:

- Hallmark greeting card**
- Quiz**
- 3 pamphlets**
- Response postcard**

Evaluation

1. 1200 Interviews

- 600 Wilson County (control)**
- 600 Pitt County (experimental)**

2. Postcards returned by older relatives

Evaluation

3. Follow-up with patients who participate in *Generation to Generation*

4. Ob-Gyn Feedback

Anticipated Long-Term Outcomes

- **Increase in mammograms**
- **Decreased number of late stage tumors**
- **Understanding that risk increases with age**
- **Beliefs changed**
- **Model developed to use relatives as a means for education**

INTERVENTION SITES

The following health care providers are participating in the intervention phase of the East Carolina Breast Cancer Awareness Program:

East Carolina University Women's Physicians
Obstetrics and Gynecology
2305 Executive Park West
Greenville, NC
252.816.1234

Physicians East/Greenville Obstetrics and Gynecology
101 Bethesda Drive
Greenville, NC 27834
252.758.4181

Greenville Women's Clinic
2251 Stantonsburg Road
Greenville, NC 27834
252.757.3131

Women's Health Center
704 WH Smith Boulevard
Greenville, NC 27834
252.830.1035

Pitt County Health Department
201 Government Circle
Greenville, NC 27834
252.413.1314

Appendix C

Age category * Obgyn main doctor?

			Obgyn main doctor?		Total
			Yes	No	
age category	under 40	Count	101	231	332
		% within age category	30.4%	69.6%	100.0%
	41 - 65	Count	53	369	422
		% within age category	12.6%	87.4%	100.0%
	over 65	Count	6	257	263
		% within age category	2.3%	97.7%	100.0%
Total	Count	160	857	1017	
	% within age category	15.7%	84.3%	100.0%	

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	93.134 ^a	2	.000
Likelihood Ratio	101.063	2	.000
N of Valid Cases	1017		

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 41.38.

Obgyn main doctor? * Had mammogram in last year

Crosstab

			Had mammogram in last year		Total
			Yes	No	
Obgyn main doctor?	Yes	Count	50	9	59
		% within Obgyn main doctor?	84.7%	15.3%	100.0%
	No	Count	343	283	626
		% within Obgyn main doctor?	54.8%	45.2%	100.0%
Total		Count	393	292	685
		% within Obgyn main doctor?	57.4%	42.6%	100.0%

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	19.780 ^b	1	.000		
Continuity Correction ^a	18.575	1	.000		
Likelihood Ratio	22.208	1	.000		
Fisher's Exact Test				.000	.000
N of Valid Cases	685				

a. Computed only for a 2x2 table

b. 0 cells (.0%) have expected count less than 5. The minimum expected count is 25.15.

Type of doctor * Had mammogram in last year

Crosstab

			Had mammogram in last year		Total
			Yes	No	
typedr	a family doctor	Count	209	143	352
		% within typedr	59.4%	40.6%	100.0%
	a general internist	Count	90	43	133
		% within typedr	67.7%	32.3%	100.0%
	an OB/GYN	Count	50	9	59
		% within typedr	84.7%	15.3%	100.0%
	a specialist	Count	19	13	32
		% within typedr	59.4%	40.6%	100.0%
	or some other type of doctor	Count	3	3	6
		% within typedr	50.0%	50.0%	100.0%
	S.C. (don't know)	Count	1	1	2
		% within typedr	50.0%	50.0%	100.0%
	None	Count	21	80	101
		% within typedr	20.8%	79.2%	100.0%
Total	Count	393	292	685	
	% within typedr	57.4%	42.6%	100.0%	

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	79.911 ^a	6	.000
Likelihood Ratio	83.757	6	.000
N of Valid Cases	685		

a. 4 cells (28.6%) have expected count less than 5. The minimum expected count is .85.